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ABSTRACT

This booklet provides an overview of Alzheimer's disease along with a description of the disease, how to find out if someone has it, and how it affects adults with developmental disabilities. It also provides information on what to do and suggests where to seek help. Specific sections discuss: (1) the etiology of the disease; (2) symptoms of Alzheimer's disease; (3) the general course of the disease; (4) other conditions that produce the same symptoms; (5) risk factors for Alzheimer's disease or dementia among people with developmental disabilities; (6) personal stories of individuals with mental retardation and Alzheimer's disease; (7) Down syndrome, aging, and Alzheimer's disease; (8) diagnosis of Alzheimer's disease; (9) places to go to be evaluated for the disease; (10) steps beyond diagnosis; (11) other concerns, such as how to serve people with Alzheimer's disease with dignity, how to help adults with the disease to "age in place," and how to prevent or defer changes in residence; and (12) resources for families and caregivers, including home care services, adult day care, respite, hospice, financial or legal aid, and local support groups. A list of resource organizations and a glossary of terms are also provided. (CR)

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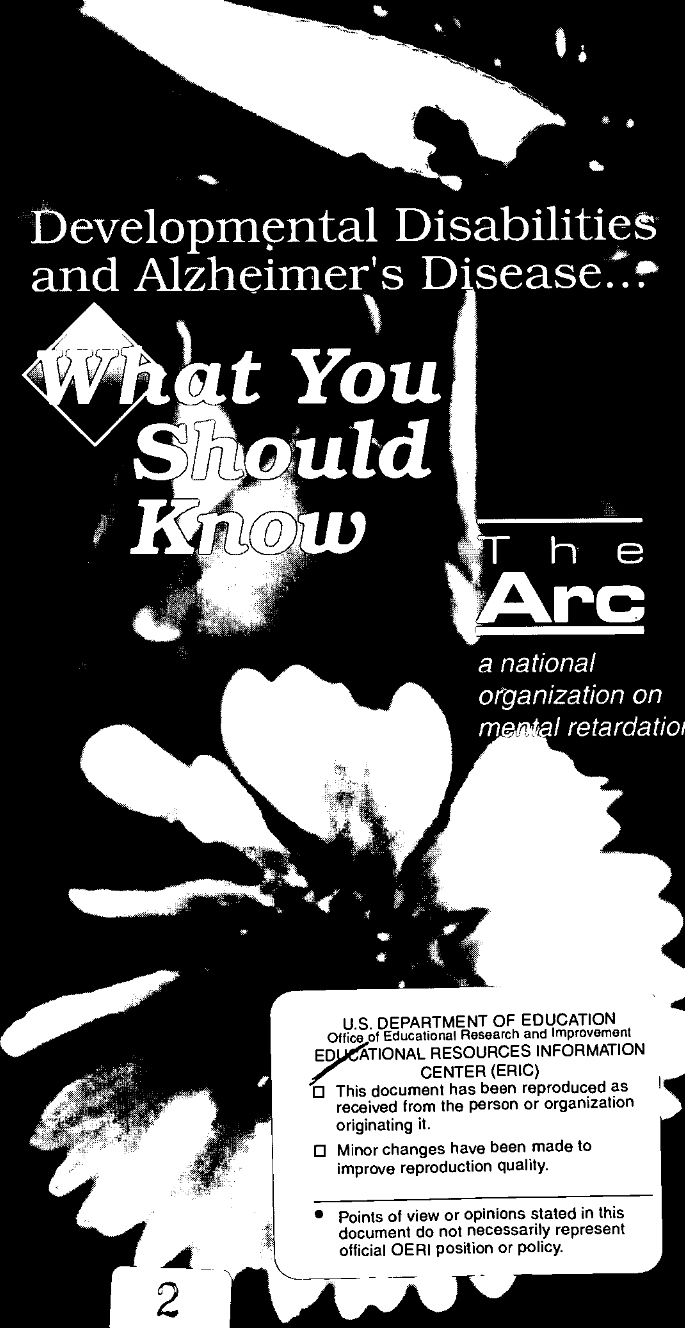

Developmental Disabilities and Alzheimer's Disease...

What You Should Know

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Developmental Disabilities and Alzheimer's Disease... *What You Should Know*

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Developed by the Workgroup on Alzheimer's Disease and Developmental Disabilities and the New York Caregiver Assistance Project in Aging and Developmental Disabilities (New York State Office of Mental Retardation and Developmental Disabilities) and published by The Arc of the United States.

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1995

Developmental Disabilities and Alzheimer's Disease...

What You Should Know

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Contents

Concerns

Are you caring for an older person with a developmental disability? Has this person shown memory loss, confusion, loss of abilities at work, unexplained changes in personality and behavior, or unexpected decline in personal skills (such as walking, bathing, toileting, dressing, or eating)? It MAY be that some of these changes are associated with the onset of Alzheimer's disease. They may also be caused by some other age-associated condition that is treatable.

This booklet can help you, the caregiver or the agency person, who is concerned about Alzheimer's disease and developmental disabilities. It describes Alzheimer's disease, how to find out if someone has it, and how it affects adults with developmental disabilities. It also provides information on what to do and suggests where to seek help.

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What is Alzheimer's disease?

Alzheimer's disease is a slowly progressive, degenerative disorder of the brain that eventually results in abnormal brain function and death. The disease was first described in 1907 by a German physician, Dr. Alois Alzheimer.

Alzheimer's disease is a disorder marked by a gradual decline in brain function that gets worse with time. It used to be assumed that this change was a normal part of aging that we called "senility." Some persons develop this condition when they are as young as 40 years of age. However, the disease is most common in persons over the age of 65. It is estimated that approximately 10 percent of persons over 65 years of age may have Alzheimer's disease and that in persons over the age of 85, up to 50 percent may be affected.

Alzheimer's disease is not a normal part of the aging process. It is not "hardening of the arteries." It is not contagious, and it is not known how it can be prevented. While the physical changes in the brain are very similar among different people, the behavioral and psychological symptoms that result are complex and may differ from person to person. These symptoms lead to a form of "dementia" which is the loss of mental skills and abilities, including self-care capabilities. As Alzheimer's disease progresses, these losses will result in total dependency for even the simplest activities.

What are the symptoms of Alzheimer's disease?

The early symptoms of Alzheimer's disease in the general population often include:

- Language problems. The person cannot find the right word or name for a familiar person, place or object. This is not the same as taking longer to recall a word. It is far more than the "occasional" slip of a name that everyone experiences.

- Loss of recent memory. The person may forget that he or she just had breakfast or has left something cooking on the stove, or may check and recheck that the bed has been made. However, recall of events from the distant past is often unaffected.

- Loss of a sense of time and place. The person may become more and more confused about what day it is, or forget the route to well-known places.

- Decline in activities of daily living. The person may exhibit an unexplained loss of activities of daily living (ADL) skills. What once was an easy task for the person may now be difficult.

- Personality changes. These may be so slight that, at first, they are difficult to notice. Some people become more quiet and withdrawn. In other cases, they may become more and more restless. Some persons may start to get angry over little things or have sudden changes of mood for no apparent reason.

What is the general course of Alzheimer's disease?

- **First (or onset stage):**

The initial symptoms often appear very gradually. There may be some minimum memory loss, particularly of recent events. The individual may experience difficulty in finding the right words to use during casual conversations. Work performance may begin to deteriorate and changes in behavior may start to become obvious. These changes may last for a period of up to five years.

- **Second (or progressive stage):**

The symptoms noted during the onset stage now become more obvious. There may be distinct problems with language abilities--this is typically the most obvious sign of movement to this stage. Persons affected may have difficulty naming objects or with maintaining a logical conversation. They may also have difficulty understanding directions or instructions. They often become easily disoriented with regard to what day it is (time), where they are (place), and who they are with (person). Confusion and the resulting frustration are often evident. Memory losses become even more pronounced. They may also begin to experience loss of self-care skills, including the ability to use the toilet (incontinence). Severe changes in personality may begin to become obvious, and their social behavior may be marked by suspiciousness (paranoia) and delusions. These changes may last for up to about twelve years.

- **Third (or terminal stage):**

Persons affected now experience substantial dysfunction. Basic skills such as eating or drinking are forgotten. Because of eating problems, many persons may experience a substantial loss of body weight (up to 20-30 percent). They may eventually lose their ability to maintain balance and walk. Their ability to recognize other persons and their environment is gone. Both long- and short-term memories are lost. At this stage, persons affected require complete 24-hour care and often become bedridden and inactive. Because of this, they are at increased risk for any infection, especially pneumonia, and consequently are far more likely to die. These changes, leading to death, may last for three or more years.

Can other conditions produce the same symptoms?

Yes. There are numerous other disorders or conditions that result in symptoms similar to those of Alzheimer's disease. Many of these conditions are treatable. It is therefore crucial to determine the cause of the symptoms and not assume they are always due to Alzheimer's disease.

If a diagnosis of Alzheimer's disease is assumed without adequate evaluation, the adult with a treatable condition may be deprived of remedies that could help return him or her to normal function. A variety of psychosocial and medical procedures must be used to rule out associated disorders as the cause of personality or behavior changes that otherwise could be mistakenly attributed to Alzheimer's disease.

It must not be assumed that someone has Alzheimer's disease because he or she exhibits some symptoms of the disease. Other common causes of these symptoms include: stroke, depression, medication reactions, thyroid disease, nutritional deficiencies, brain tumors, head trauma, subdural hematoma, and normal pressure hydrocephalus.

Although Alzheimer's disease is the most common cause of dementia, it is only one of many causes. There are also "related disorders" that cause various forms of dementia. These include multi-infarct dementia (a cortical dementia) and conditions like Huntington's disease, Parkinson's disease, and Creutzfeldt-Jakob disease (which are sub-cortical dementias).

There are also "associated disorders," such as thyroid abnormalities, arthritis, hearing loss, temperature sensitivity and sleep pattern changes, that may occur at the same time as Alzheimer's disease but which are not caused by Alzheimer's disease. These conditions may be reversible or treatable. They result in dementia-like symptoms

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but do not actually cause the permanent brain changes that result in dementia.

Risk factors for Alzheimer's disease or dementia among people with developmental disabilities

"Developmental disabilities" describe mental and physical disabilities that occur before age 22, impede normal growth and development, and which continue into old age. Mental retardation, cerebral palsy, epilepsy, autism, and certain physical and neurological impairments are examples of various categories of developmental disabilities.

Most adults with a developmental disability are at the same risk for Alzheimer's disease (or other forms of dementia) as are individuals in the general population. However, there are individuals with a developmental disability who are at greater risk of developing the disease when the following are present:

- If the individual is over 40 years of age and has Down syndrome.

- If the individual has had some form of head injury, especially severe or multiple injuries.

- If the individual has a history of Alzheimer's disease in his or her family.

The presence of these factors does not necessarily mean that Alzheimer's disease (or some other form of dementia) will occur. However, the presence of one or more of these risks should alert the care provider to the increased probability of the person with a developmental disability developing this disease. When there is suspicion about the presence of Alzheimer's disease, medical follow-up must be done to ensure a proper differential diagnosis.

Studies at the New York State Institute for Basic Research in Developmental Disabilities have shown that the rate of occurrence of Alzheimer's disease among persons with a developmental disability appears to be about 2 to 3 percent of adults age 40 and older. People with Down syndrome make up about 60 percent of the adults with mental retardation who show signs of probable Alzheimer's disease.

Some personal stories

Stephanie L.

Over the last two years Stephanie L. has lost a great deal of her functioning ability. Stephanie L., who is 54 years old and has Down syndrome, now has trouble with feeding, toileting, dressing and communicating--things she could do quite well just a while ago. The staff at the home where she lives are doing a remarkable job in providing the hands-on care that she now requires and have drawn upon a variety of community resources to help her. They have also taken special training offered by the local Alzheimer's Association and have helped her get special supports from a local health adult day program. Her case manager has spoken with several private care agencies and is exploring the use of a personal care aide. The personal care aide would be used to provide individualized attention to Stephanie L. and offer some respite for the staff and other individuals living in her home. Other support services, like the local Alzheimer's support group and the local hospice, are being used to help maintain Stephanie L. in her home for as long as possible.

Francis G.

Not long ago, Francis G., who is 68, was employed in a sheltered workshop. As a young adult he was diagnosed with moderate mental retardation. Throughout most of his life he was productive, independent, and very aware of his personal appearance and how he conducted himself in public. He learned of a program at the community senior center a couple of years ago, began attending two days a week and then decided to participate daily. Not long after he became a regular participant, his behavior became erratic and he began losing a sense of time and place. He became incontinent, and his appearance and personal care deteriorated. His temperament became offensive. He would not agree to do most of the things he was asked to do. He became forgetful, angry, and difficult around the other people at the center and the staff. Any change in schedule brought complaints. His abilities and sense of reality deteriorated rapidly. Eventually, he could no longer attend the senior center, nor live with his relatives, and was admitted to a local nursing home to meet his increasing physical needs.

Marion B.

A woman with Down syndrome, Marion B. was until recently very sociable, aware of herself, and articulate in conversation. Her sense of humor, insight, and independent spirit rapidly vanished within two years after she reached age 59. The family with whom she lived and the staff at the day program she attended noted ever-increasing confusion and loss of self-care abilities. Her sleep pattern changed, and she began to stay awake all night. She tried to eat waste, and began talking to her own image in the mirror, insisting it was "Susie," an old friend. In a short time, she could no longer live in the family home, which had been hers for ten years, and had to move to a group home. Even this was not enough to meet her now intense need for personal care, and soon she was admitted to the Alzheimer's disease care wing of a community nursing home.

Down syndrome, aging and Alzheimer's disease

People with Down syndrome may experience health problems as they age that are different from those experienced by older persons in the general population. The presence of extra genetic material found among persons with Down syndrome may lead to abnormalities in the immune system and a higher susceptibility to leukemia, seizures, cataracts, respiratory illness, and heart conditions. Persons with Down syndrome also experience premature aging--that is, they show physical changes related to aging some 20 to 30 years ahead of persons of the same age in the general population.

With increased age, persons with Down syndrome may experience "typical" hearing loss and vision changes that are "expected to accompany being older," but will do so 20 to 30 years before other persons in the general population. Vision problems may be mostly due to cataracts. There may also be problems with motor abilities and changes in the skin, nerve, muscle, digestive, and urinary systems. Compared to age peers, people with Down syndrome have higher rates of Alzheimer's disease. This may be another example of age-related changes occurring earlier in persons with Down syndrome than would be expected in persons in the general population. Adults with Down syndrome are often in their mid to late 40s or early 50s when symptoms may first appear, while symptoms first appear in persons in the general population beginning in the late 60s.

Although about 20 to 40 percent of adults with Down syndrome show the behavioral symptoms of dementia, upon autopsy nearly all older adults with Down syndrome show the brain changes associated with Alzheimer's dementia. The progression of the disease takes, on the average, about eight years--

somewhat less time than among persons in the general population. Men and women seem to be equally susceptible.

The symptoms of the disease may be expressed differently among adults with Down syndrome. For example, at the early stage of the disease, memory loss is not always noted, and not all symptoms ordinarily associated with Alzheimer's disease will occur. Generally, changes in activities of daily living skills are noted, and there may be the onset of seizures when there had been no seizures in the past. Cognitive changes may also be present, but they are often not readily apparent or they may be ignored because of limitations in the individual's general functional level.

Is there a test for Alzheimer's disease?

There is no single diagnostic test for Alzheimer's disease. If the presence of Alzheimer's disease is suspected, a complete physical examination and more frequent medical, neurological, and

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psychological evaluations are strongly recommended to establish the progressive nature of the symptoms, particularly for adults with a developmental disability.

A "definitive" diagnosis can only be made at the time of autopsy. The numerous tests and evaluation procedures will result in a "possible" or "probable" diagnosis of Alzheimer's disease.

To make a probable diagnosis of Alzheimer's disease, it is necessary to observe a well-documented progression of symptoms and rule out any other possible conditions or disorders. To help secure such a probable diagnosis, complete evaluations must be performed periodically. Such evaluations or tests are necessary to rule out conditions that are not Alzheimer's disease, or are reversible forms of dementia.

A complete evaluation should include:

- A detailed medical history, provided by a family member, caregiver or someone else well acquainted with the individual. This is the best way to determine accurately whether or not there has been progressive deterioration and personality changes, problems with memory, and difficulty with daily activities. As much as possible, the person should be involved in this process and asked what he or she feels is changing.

- A thorough physical and neurologic examination, including the testing of sensory-motor systems, to rule out other disorders.

- A "mental status test" to evaluate orientation, attention, recent recall and the ability to calculate, read, write, name, copy drawing, repeat, understand and make judgments. Mental status evaluations may not be useful with individuals with preexisting cognitive limitations, such as severe mental retardation. Because of this, mental status examinations need to take into account the individual's past history and abilities and should never be the sole clinical assessment.

- A psychiatric assessment to rule out the presence of a psychiatric disorder, particularly depression.

- Neuropsychological testing to measure a variety of functions that include memory, orientation, language skills, intellectual abilities, and perception.

- Routine laboratory tests, including blood work, health exams, such as urinalysis, chest x-ray, electroencephalography (EEG), and electrocardiography (EKG), as well as certain specialized tests as deemed appropriate. Imaging techniques, such as CT (computerized axial tomography) and MRI (magnetic resonance imaging), can be useful in showing progressive brain atrophy and helping to rule out other selected dementias. However, these techniques are costly and are mostly used in research.

Although the above assessments apply to most people with a developmental disability who may be suspected of having Alzheimer's disease, the sole use of mental status and psychiatric assessments is inappropriate, especially for persons with severe mental retardation. It is recommended that, at minimum, annual or more frequent evaluations and measures be used to look for changes in existing skills.

Where does someone go to be evaluated for possible Alzheimer's disease?

A good place to start is with the person's physician. A neurologist, geriatrician, or an internist can also be a valuable resource.

States may have specialized centers for the evaluation and treatment of people with Alzheimer's disease. These centers may provide geriatric evaluations and assessment procedures plus other services. States may also have specialized services for people with developmental disabilities who are aging. These may include special clinics of local mental retardation, mental health or aging agencies, and university affiliated programs in developmental disabilities.

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To find Alzheimer's disease services in your area, contact the city or county health department, local mental health/mental retardation centers, hospitals, area agency on aging or the information and referral service that many cities provide through the United Way or other organizations. You may also be able to locate these services by looking in the telephone book under "Health" or "Social" Services. These same resources may also be able to refer you to any state or community programs or clinics which specialize in services to older people with developmental disabilities.

What are the steps beyond diagnosis?

Once the suspicion of Alzheimer's disease has been clinically confirmed, the person's family, caregiver, or paid providers may need to make changes in the person's daily routine.

First and foremost, the person must feel safe and secure in his or her environment. As a result of the complications associated with Alzheimer's disease, what may have been comfortable and familiar for the individual will become unrecognizable and result in unpredictable behavior. For example, some persons may have changes in behavior that make them seem suspicious and delusional.

To help with the changes in behavior, consider the following:

- Emphasize maintaining abilities, particularly those affecting dignity (e.g., toileting, eating), rather than trying to teach new skills.

- Keep changes in environment and daily routine to an absolute minimum.

- Simplify routines and reduce choices to minimize feelings of anxiety and frustration.

- Use patience and redirection, keep verbal requests simple, and provide general supportive care.

- Maintain self-awareness by using reminiscing and talking about past experiences, when appropriate.

- Help the person maintain his or her orientation by naming events for the day, reminding him or her of the day, time and place, and repeating the names of others around him or her. Try not to "force" him or her back to your reality, but also don't allow a move into a delusion that you may be inadvertently reinforcing.

- Reassure the person daily, even when there is no response.

- Try to understand the words and symbols the person is using in communicating. Be patient, and don't try to force the person to understand your means of communicating; adapt to his or hers.

- Provide appropriate foods and liquids to maintain nutrition and hydration.

- Respond to suspicions and delusions with reassurance.

- Consult a physician about stopping nonessential medications and, when appropriate, assume responsibility for giving the person his or her needed medications.

- Minimize toileting accidents by establishing a toileting routine.

- Convey affection and protection by a quiet voice and use touch for reassurance and praise.

To help with changes in program practices, consider the following:

- Provide a familiar and safe environment, and provide closer supervision to minimize confusion and disorientation.

- Maintain present level of independence by increasing staff supervision, prompts, and hands-on care.

- Modify the individual's program or support plan to anticipate changing activities of daily living (ADLs) and supervision needs.

- Monitor and document increased episodes of confusion, disorientation, or memory lapses to become more prepared as they repeat in the future. Continue assessments for mobility, safety, and ADL needs.

- Inform staff, family members, and caregivers close to the person of changes and strategies in the plan of care.

- Seek to identify "triggers" that result in inappropriate or dangerous behavior and try to minimize the likelihood that they will occur in the future.

What are some other concerns?

Other concerns may include how to help staff adapt programs and services to changes that result from Alzheimer's disease, especially how to serve that person with dignity, how to help adults with possible Alzheimer's disease "age in place," and how to prevent or defer changes in residence.

In some programs, particularly those governed by state regulations requiring active treatment, staff may need to emphasize a different approach to care. The program plan should be adapted to reflect the behavioral and physical changes the persons may experience that result from the various stages of the disease. Program philosophies that emphasize choice-making may need to be reevaluated, because making choices can be very confusing and frustrating for someone with Alzheimer's disease.

As the disease progresses, staff need to be prepared to adapt treatment practices to the changing needs of the individual with probable Alzheimer's disease. These adaptations should reflect a knowledge of the course of Alzheimer's disease and the potential for diminishing abilities among self-care, communication, and orientation skills. A balance should be maintained between compensating for loss of skills and maintaining development.

Early signs and symptoms of Alzheimer's disease do not necessarily warrant changes of a program or residence, particularly if the older adult is already used to attending or living in a familiar place. The adult should be allowed to "age in place" with dignity and respect. Many adaptations can be made to the person's program or home environment to make it safe and practical. Modifications in activities and supervision may be necessary.

Many caregivers will continue to provide care no matter how difficult it is. However, with the advanced progression of the disease, particularly when there is total loss of self-care skills and mental abilities, some caregivers or staff may be faced with the difficult decision of whether or not to accept admission to a facility that can provide appropriate long-term care.

The need to change residence can be reduced by providing supports greater than those already being provided to the individual. Providing such supports should always be considered prior to a change in the person's residence. Those at jeopardy of having to change residence as the disease progresses include persons who are living:

- With a caregiver who may be unable to continue supervision and supports on his or her own, unless he or she receives additional assistance.

- Alone or with a spouse or friend and who may be at risk for personal injury due to memory loss, disorientation, and personal skill deterioration.

- In a residence where the person's needs have substantially changed due to an increased need for supervision and nursing care, the individual's behavior has a marked negative effect upon others in the residence, or the individual's overall deteriorating condition transcends the level of care which can be provided in the residence.

Where can families and caregivers of a person with a developmental disability and Alzheimer's disease get help?

As a family member, you may need to plan for future care in a residential setting that is equipped to provide for a person with a developmental disability who has Alzheimer's disease. However, until that time, many things can be done to provide in-home supports.

Many family members and caregivers of an adult with a developmental disability have provided a lifetime of affection, support, and care while watching the individual progress and become more independent. It is particularly difficult for a family member or caregiver to watch his or her relative lose skills associated with the onset of Alzheimer's disease. Therefore, it is very important to obtain services and supports during this difficult time.

Certain specific services may be helpful in supporting the care that you are providing:

- Home care services - These include having a homemaker assist in the home or having a nursing aide provide personal care to the adult. It may also include home-delivered meals, friendly visiting, and the services of a senior companion. For the names of agencies that provide home care services in your community, call your local area agency on aging or look in the yellow pages of your telephone directory (generally under "Home Health Services").

- Adult day care - Available in many communities, this program may offer a brief respite from caregiving and an opportunity for the adult to become involved in different day activities. For names and locations of adult day care programs in your community, call your local area agency on aging, your county health department, the local chapter of The Arc or other disability agency, or look in the yellow pages of your telephone directory (generally under "Day Care Centers-Adult" or "Elderly Person Services").

- Overnight or weekend respite - Either in the home or at another setting, respite offers a chance for the caregiver to take a vacation or other short break from caregiving. For names of agencies that provide respite services in your community, call your area agency on aging, the local or state mental retardation agency, local chapter of The Arc or other disability agency, or look in the yellow pages of your telephone directory (generally under "Social and Human Services").

- Hospice - This includes special support services in the home or within a specialized hospice setting during the last six months of life. Hospice services are for persons who are terminally ill as well as for their caregivers. For the name of the hospice in your community, contact your local health department or look in the yellow pages of your telephone directory (generally under "Hospices").

- Financial or legal aid - This includes aid in arranging for payment for care and help in settling legal concerns, such as wills and trusts. For information on how to obtain such aid, consult your local area agency on aging, local chapter of The Arc, or other local disability agency.

- Local support groups - These include counseling or other group supports with persons in a similar situation. For information on how to obtain such aid, consult your local Alzheimer's Association or local area agency on aging.

Some area agencies on aging or local senior services agencies maintain special caregiver assistance programs. Some of these include special supports for parents with a son or daughter with a developmental disability. These programs can help you obtain specialized in-home services and other supports. To receive more information regarding any of these services, call your local area agency on aging or local chapter of The Arc.

If you are a staff member providing residential or day services for an individual with a developmental disability whom you suspect may be showing symptoms of Alzheimer's disease, you can turn to your agency for guidance and assistance. You can also call your local area agency on aging, local office of your state mental retardation and developmental disabilities agency, local chapter of The Arc, local Alzheimer's Association, or any local Alzheimer's disease or dementia assistance program or service for advice.

If you are providing care to an individual with Alzheimer's disease, you may want to participate in a support or educational group. These groups are for people in similar caregiving situations who meet regularly to share experiences and advice with each other and learn about resources available to them.

To find out about support and educational groups and related resources in your area, call your local area agency on aging, mental retardation state agency, local chapter of The Arc or other disability agency, local Alzheimer's Association, or look in the yellow pages of your telephone directory (generally under "Social and Human Services") or in the white pages business listings.

Where can you obtain assistance?

Caring for someone with a developmental disability who may have Alzheimer's disease can be a long and difficult task. There are many helpful resources that can assist families and other caregivers of people with Alzheimer's disease. If you need help or just want to learn more about Alzheimer's disease, contact:

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- The Alzheimer's Association. This is the only national voluntary organization dedicated to conquering Alzheimer's disease through research and by providing education and support to people with Alzheimer's disease, their families and caregivers. The Alzheimer's Association has local chapters throughout the United States, plus produces a wide-range of materials on this disease. To locate the nearest local chapter, or to get more information or receive materials, contact the association at 1-800-272-3900. You can also write the Alzheimer's Association at 919 North Michigan Ave., Suite 1000, Chicago, Illinois 60611-1672.

- Your area agency on aging. In some communities, this agency may be called by a different name, such as office or department for senior citizen affairs or senior services. Look for the telephone number in your local telephone directory. Most area agencies on aging also issue a community resource directory which lists many Alzheimer's disease assistance resources.

- Your state office or agency on aging. These are also called state units on aging (SUAs). Contact your SUA and explain your situation and ask for suggestions. Don't forget to ask for the number of your area agency on aging. To contact your state aging agency look in the state government listings of your local telephone directory.

- The Alzheimer's Disease Education and Referral Center (ADEAR). Operated by the National Institute on Aging, the ADEAR can provide some helpful information through its variety of publications. You can write the Center at P.O. Box 8250, Silver Spring, MD 20907-8250 or call 1-800-438-4380.

- The Arc (formerly the Association for Retarded Citizens of the U.S.) is the country's largest voluntary organization committed to the welfare of all children and adults with mental retardation and their families. The Arc has chapters throughout the United States and provides publications and other useful information. You can write The Arc at 500 E. Border St., S-300, Arlington, TX 76010 or call 1-800-433-5255, TDD 1-800-855-1155 and ask operator to call collect (817) 277-0553.

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Some terms . . .

activities of daily living (ADL) - routine activities engaged in during the course of the day, such as washing, grooming, dressing, eating and cooking.

associated disorders - conditions that are present at the same time.

Alzheimer's disease - a progressive neurodegenerative disease characterized by loss of function and death of nerve cells in several areas of the brain, leading to loss of cognitive function such as memory and language.

autopsy for Alzheimer's disease - gross and microscopic examinations of brain tissue after death to confirm the clinical diagnosis.

cataracts - a clouding of the lens of the eye which blurs vision.

cognitive changes - changes in thinking abilities (such as reasoning).

cortical dementia - dementia associated with impairment of that part of the brain that affects memory, attention, reasoning, and abstract thinking.

Creutzfeldt-Jakob disease - a neurological disease, lasting about three years, that leads to rapid loss of memory, speech and writing skills, reasoning abilities, and a majority of bodily functions prior to death.

definite Alzheimer's disease - a level of diagnosis that is supported by evidence of neurological changes present at autopsy.

delusions - beliefs maintained even when they are contrary to truth.

dementia - widespread loss of mental skills and abilities of such severity that capability to care for oneself is lost.

developmental disability - any mental or physical functional impairment that occurs before age 22, impedes normal growth and development, and which continues into old age.

differential diagnosis - clinical evaluation of possible causes of dementia to rule out all other factors before settling on Alzheimer's disease.

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Down syndrome - a chromosomal abnormality of chromosome 21 associated with mental retardation.

functional capabilities - what a person is able to do.

head injury - an impact to the head which causes injury to the brain and results in long term damage and impairment.

hospice - a philosophy of care that focuses on relief of symptoms, pain control, and providing a variety of supports through the period of dying.

Huntington's disease - a genetically linked neurological disease that leads to loss of movement in the face, arms and legs, loss of speech and use of the brain and leads eventually to dementia.

incontinence - inability to control bowel and bladder functions.

leukemia - a fatal disease of the white blood cells and blood-forming organs.

multi-infarct dementia - dementia due to loss of blood supply in the brain after a series of small strokes.

hydrocephalus - enlargement of the head due to the accumulation of fluid around the brain.

paranoia - behavior characterized by extreme suspiciousness and delusions.

Parkinson's disease - a neurological disease that leads to tremors, muscle rigidity, and slowing of all body motions.

possible Alzheimer's disease - a level of diagnosis that is supported, but with a degree of uncertainty, by the person's medical history, and by neurologic, psychiatric, and clinical examinations, neuropsychological tests, and laboratory studies.

premature aging - physical changes related to aging occurring ahead of what would be normally expected for a person's chronological age.

probable Alzheimer's disease - a level of diagnosis that is supported with relative certainty by the progressive deterioration of specific cognitive functions, motor skills, and perception, impaired activities of daily living and altered patterns of behavior, family history of similar problems, and laboratory findings of physical changes.

related disorders - conditions that are similar in nature to the main condition but occur for a different reason.

sensory-motor - those aspects of movement and sensation.

subcortical dementia - dementia associated with impairment of the lower part of the brain that affects speed of motor and mental processes.

subdural hematoma - a hemorrhage under the dura or membrane covering the brain and spinal cord.

Some helpful resources . . .

Caring for Alzheimer's Patients: Caregivers Practical Help. New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223

Alzheimer's Disease and Down Syndrome (Fast Facts on Aging #1). The University of Missouri-Kansas City Institute for Human Development, 2220 Holmes Street, 3rd Floor, Kansas City, MO 64108-2676

Alzheimer's Disease: A Family Survival Guide. Alzheimer's Disease Research, 15825 Shady Grove Road, Suite 140, Rockville, MD 20850

Alzheimer's Disease: A Family Information Handbook. Health and Welfare Canada, c/o Alzheimer Society of Canada, 185 Bloor Street East, Suite 222, Toronto, Ontario M4W 3J3 Canada, (416) 927-1580

Alzheimer's Disease - A Special Report. Harvard Medical School, Health Publications Group, Department ALZ, P.O. Box 380, Boston, MA 02117

A Path for Caregivers. American Association of Retired Persons, 601 E Street, N.W., Washington, DC 20049

Caring for the Alzheimer's Patient at Home: Tips for Coping. Alzheimer's Disease Research, 15825 Shady Grove Road, Suite 140, Rockville, MD 20850

The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses and Memory Loss in Later Life. Johns Hopkins University Press, Baltimore, MD 21218

Practice Guidelines for the Clinical Assessment and Care Management of Alzheimer Disease and Other Dementia Among Adults with Mental Retardation. American Association on Mental Retardation, 444 North Capitol Street, N.W., Suite 846, Washington, DC 20001-1570

Down's syndrome and Alzheimer's disease. (1994) Down's Syndrome Association, 155 Mitcham Road, London SW17 9PG, England

Q&A: Alzheimer's disease and people with mental retardation. (1995) The Arc, 500 E. Border St., Suite 300, Arlington, TX 76010

Some things to remember. . .

- Alzheimer's disease is a slowly progressive degenerative disease that eventually results in death. It is not part of normal aging.

- Symptoms of Alzheimer's disease include losses in language, recent memory, orientation, activities of daily living, and changes in personality.

- Many conditions that are treatable produce symptoms that are similar to Alzheimer's disease. It is important for adults showing signs of dementia (loss of mental disabilities) to have a complete medical workup.

- Persons with a developmental disability are at greater risk for Alzheimer's disease if they are older than 40 and have Down syndrome or come from a family with a history of Alzheimer's disease.

- Persons with Down syndrome appear to age more rapidly than other persons in the general population and thus are at greater risk for Alzheimer's disease than are peers of similar age. Although only some 20 to 40 percent of adults over age 45 show the behavioral signs associated with symptoms of Alzheimer's disease, nearly all show the brain changes associated with Alzheimer's disease at death.

- A complete evaluation and several periodic reviews of behavioral changes are necessary to develop a diagnosis of Alzheimer's disease. These should include, at minimum, a comprehensive history, physical, neurologic and neuropsychiatric assessments, and a mental status exam.

- Persons who have Alzheimer's disease may be helped by care management programs. These help to maintain the person's highest level of functioning.

- To minimize confusion and agitation caused by dementia, changes in the residence and other familiar activities should be avoided.

- Staff, family and care providers should adapt the plan of care to reflect the person's diminishing abilities and focus on the person's remaining strengths.

- Many services are available to support the care that staff and family provide to an individual with Alzheimer's disease, including home care, adult day care, overnight and weekend respite, hospice, financial and legal aid, and family support groups.

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