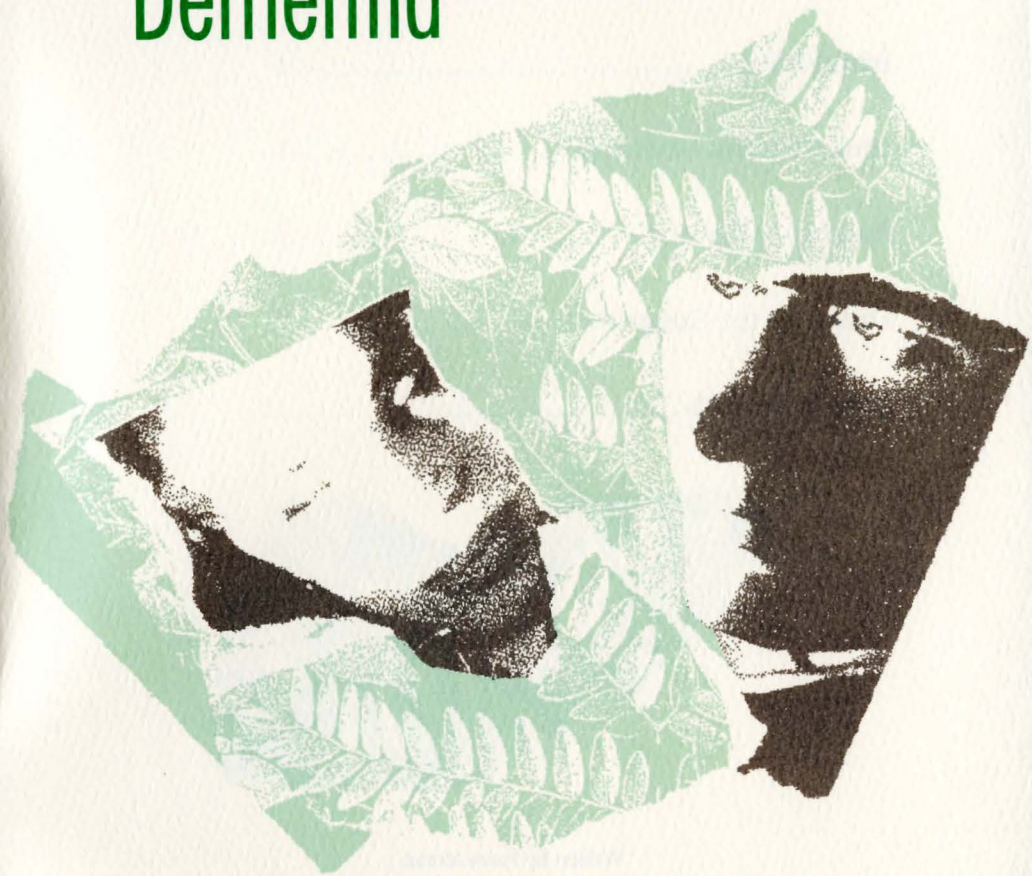
RESOURCES

All 800 numbers are toll free. Please dial "1" before each number.

National AIDS Hotline.....800-342-2437
National SIDA Hotline.....800-344-7432
National Deaf Hotline (TDD).....800-243-7889
National AIDS Clearinghouse.....800-458-5231
National Drug Hotline.....800-874-2572
ACTIS (Drug Trials).....800-TRIALSA
AmFar (Drug Trials).....212-719-0033
Project Inform.....800-822-7422
Pediatric & Pregnancy Hotline.....212-430-3333

Living With Dementia



A Guide for the Extended Family

Contents

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INTRODUCTION

The emotional challenge of caring for someone with dementia is a difficult one. This guide can help you cope by giving you practical solutions to problems you are likely to encounter in caring for your loved one.

Because caregivers often put their own needs last, this booklet encourages you to learn ways to reduce stress and take time for yourself whenever possible. It also discusses the legal steps that safeguard the rights of someone with dementia while enabling those who care about him to act on his behalf.

UNDERSTANDING DEMENTIA

What Causes Dementia?

Dementia can be caused by different types of health problems. Alzheimer's disease, head injury, HIV disease and other illnesses all cause some form of dementia. The appearance of dementia in a person with HIV infection is due to a direct infection of the brain by the virus that causes AIDS. This virus is known as the **H**uman **I**mmunodeficiency **V**irus (**HIV**). A person with HIV-related dementia may have mild or severe symptoms.

When someone has a mild infection, his condition is called **HIV-associated minor cognitive/motor disorder.** If his infection is severe, his condition will be referred to as **HIV-associated Dementia Complex** or **AIDS-related Dementia Complex** (**ADC**).

Symptoms

HIV-related dementia affects the person's ability to think clearly, concentrate, and remember details about the recent past. At the same time, he may remember details about things that happened many years ago.

He may experience difficulty with certain tasks like tying his shoes or maintaining his balance. He may also seem more withdrawn, less interested in life and the people around him. He may seem depressed.

Sometimes the person may not speak clearly or forget certain words. He may also notice changes in his handwriting and poor coordination in general. Most often people can still function at home and on the job, depending on the type of work performed and the severity of their symptoms.

If the infection is more severe, the person may become unable to follow a conversation, read a book, or remember appointments. He may become very anxious, suspicious of others, and easily irritated. Severe depression may develop. Walking may become very difficult. The person's overall safety becomes a serious concern. Driving a car or being left alone for long periods becomes dangerous.

People with advanced dementia become unable to take care of themselves and will need 24 hour care. They may become incontinent (unable to control bowel and urinary movements) and bedridden. Some people may appear psychotic.

How symptoms of dementia appear varies from person to person. Sometimes the illness develops slowly, progressing from a mild infection to a very severe one. For others, the illness progresses very quickly; still others experience symptoms that come and go. Most people experience only mild symptoms that never progress to full-blown dementia.

Getting a Diagnosis

Some of the symptoms described above are often stress-related and have nothing to do with dementia. When people are under emotional stress they often become forgetful, distracted, depressed, anxious or quick to react to minor irritations with anger. If you are noticing any of these symptoms in your loved one, urge him to talk with his physician. The problem may not be related to dementia.

There are also other AIDS-related illnesses that can cause some of these symptoms. They include toxoplasmosis, cryptococcal meningitis, and CMV encephalitis. A careful diagnosis will determine the appropriate treatment. Diagnostic tests include careful questioning of the patient and those close to him, blood tests, a physical exam, a spinal tap, a CAT scan and an MRI.

Treatment

While there is no cure for dementia, many physicians are using antivirals, antipsychotics, antidepressants, or psychostimulants to treat symptoms associated with it. Antivirals like AZT and ddI have been used to prevent or slow the progress of the disease. However large studies have not been done with these drugs.

There are rehabilitation programs that help people with improving coordination, memory and speech patterns. Your social worker will be able to help you locate these programs in your area.

The most important form of care that concerns the extended family is the personal care that you offer. The following section, **Practical Caregiving**, covers important concerns if you are going to care for the person at home.

PRACTICAL CAREGIVING

For most people, loss of control over one's life and the ability to do things for oneself brings a loss of self-esteem and personal dignity. Most people become fearful and anxious about being able to handle everyday living. Many people also feel angry and resentful over their increasing dependence on others. It is important for the family to know just how much help to provide. Too much independence may leave the person open to safety hazards; too little may lower the person's sense of self-worth. Care must be taken not to increase the person's sense of helplessness or confusion. At the same time, being sensitive to your own needs is very important.

Talking with the individual, his physician, social worker, emotional support volunteer or other friends and family can help determine just how much assistance the person needs. Help with everyday tasks can be divided into specific areas to make them more manageable. Taking the time to assess the situation as carefully as possible will help to lessen stress for the individual and the family.

Building a Support Team

Call together all those who are personally concerned about your loved one's care. Different people can schedule time to do specific tasks, like shopping, housekeeping, bathing and personal grooming, cooking and preparing meals, etc.

Call your local AIDS agency to find out what community services are available for people who need this type of personal care or who are homebound. In some areas, certain agencies provide practical support volunteers who will shop, perform household chores and sometimes cook for someone with HIV disease. Everyone who participates in this effort is part of a "support team". Your social worker will be able to tell you what is available. Here is a list of some of the services that you may want to learn about:

Practical Support: Usually volunteers, these people can help with shopping, housekeeping, taking care of pets, and other daily or weekly chores.

Home Health Aides: These people are paid workers who help with personal hygiene, preparing simple meals, changing bed linens, etc. They cannot administer medication.

Visiting nurses: Visiting nurses can help your family plan your loved one's care. Nurses can administer drugs and give other forms of medical treatment. Check your insurance coverage to see what type of home health care is covered. Call your local visiting nurses association to find out more.

Meals on Wheels & other food services: Several AIDS agencies offer home food delivery for people with HIV. Many cities offer free meal delivery to anyone who is too ill to get out to shop and cook their own meals (Meals on Wheels). Call your local AIDS agency or department of public health to learn about services in your area.

Adult Day Care: In some areas, adult day care is being offered to people with HIV who cannot manage on their own. They are well enough to be taken to a day care facility where they can participate in a structured rehabilitation program. This type of program provides the caregiver with a much needed break from the stress of caregiving.

AIDS Legal Services: This is a panel of lawyers who offer services either for free or at low cost to people with HIV.

Emotional Support: Certain AIDS agencies train volunteers in providing peer support to people with HIV. Many also offer support groups and private counseling provided by social workers or psychotherapists.

Caregiver Support Groups: This is an important source of support for you. Some of these groups are specifically for caregivers who are not HIV-positive and others are for those who are positive or have AIDS themselves. Being able to talk with other people who are going through the same experience can provide much needed support.

First Steps

There are several things you can do to help someone cope with tasks that have been affected by a loss of memory and impaired physical coordination.

Make lists. It is helpful to make a list of what is needed at the store, what errands need to be run, or what appointments need to be kept. Having a written list helps the person to be as self-reliant as possible.

Slow down. Encourage the person to do things slowly, one task at a time. You might also encourage him to state out loud what he is trying to do. This will help him focus on each step.

Keep him mentally involved. Encourage him to be mentally alert by playing cards, video games, word games or puzzles.

Get plenty of rest. Getting overtired will make most of his symptoms worse. Scheduling appointments and other tasks early in the day after a good night's sleep will be helpful.

Avoid overcrowded, noisy environments. Too many loud distractions such as shopping in a crowded mall, eating out in a noisy restaurant or going to a party may overstimulate and confuse him.

Get plenty of exercise. Exercise will stimulate the mind and body and help keep the person involved in the world. Walking in quiet, natural surroundings is helpful.

Help him with difficult tasks. Many people with dementia can no longer manage things like balancing their checkbook or keeping track of their medication. An automated pill box will help them with their medication. Having a friend balance their checkbook will help them with their finances. (See the section on **Legal Safeguards** for information on Durable Powers of Attorney.)

The Environment

Because people with dementia tend to lose their ability to make changes easily, new situations become very frightening. Their difficulty in handling these situations becomes frustrating. This frustration eventually leads to anger. Because some people with dementia experience something called "disinhibition," they may tend to express angry feelings very abruptly. These feelings may seem out of place.

They will also experience difficulty in getting around their own home, bumping into things, leaving things on the stove or falling down steps. Because they have difficulty in controlling their behavior and coordinating their own movements, the environment around them - and the people in it - have to change. Here are some things you can do:

- Keep the home uncluttered and well organized. Remove throw rugs and other things that the person may trip over. Use night lights. Put labels near doorways, on cupboards, next to closets, to remind the person what is in each area.

- Install extra locks on outside doors to prevent the person from wandering off. Remove locks on doors that don't need them so the person doesn't lock himself in the bedroom or bath.

- Remove knobs from the stove to prevent the person from turning on the stove when home alone. Lock up hazardous appliances like the iron, poisonous household cleaners or medications.

- Showering and bathing may have to be supervised. Use tub mats and handrails whenever possible.

- Have a daily routine that stays the same. This keeps the person oriented and enables him to stay focused on things he can do, rather than being concerned about things that have become too confusing. Keep favorite photos, family albums and music available to stimulate positive memories and familiar feelings.

- Talk slowly and clearly. Get the person's full attention and speak slowly and clearly. Eliminate background noise, like the TV. Use gestures to emphasize what you are saying. Ask him to repeat what you said to be sure that you have been understood.

- Make daily tasks easy to complete. Wearing clothes and shoes that are easy to put on and take off is very helpful. Using cups instead of bowls and spoons may also be helpful. Preparing finger foods and presenting foods already cut into small pieces will lessen accidents.

Emotional Changes

Many of the emotional changes seen in people with dementia are beyond the person's ability to control. Some of these changes may be very dramatic and frightening to you.

In addition to problems associated with disinhibition, some people with advanced dementia may become extremely irritable and very angry, reacting harshly to minor annoyances. They may lash out with little apparent reason. This type of episode has been called 'catastrophic anxiety.'

If this happens, you may want to remove the person from the situation for a period of time. Try to figure out what caused the outburst. It might have been a sudden loud noise or too many people talking at once. He might have been trying to do something that was too complicated for him. Try to simplify tasks and keep his environment as quiet as possible.

It is difficult for caregivers to remain calm and untroubled by these outbursts. It is helpful to remember that the person with dementia cannot control his behavior and is not aware of the impact of his actions on other people. He may not realize that he

does not function as well as he used to. He may even minimize the hazards of driving or cooking on his own or act very silly one minute and very suspicious the next.

Some people may experience hallucinations or imagine that they are the president of Ford Motor Co. If any of these symptoms start to occur, report them to his physician. They may be caused by dementia, medication or a high fever. Many of these symptoms can be treated.

Communication

Because the person with dementia is so sensitive to his environment, it is helpful to learn to communicate with him in certain ways. Very often the person with dementia says things in alarming, even disturbing, ways. Thinking about how you will respond in advance will help lessen any tension in a specific situation. You can re-direct the person's attention away from what might become an emotional crisis.

If the person with dementia accuses you of something, like stealing something or not giving him something that may harm him, try not to react too defensively. How we say something is often as important as what we have to say. You might offer to help him find what he is looking for.

Sometimes the strain of caring for someone with such a complex problem puts the caregiver on edge. Thinking through what we are about to say seems too difficult. Being aware that the person with dementia will sometimes react to simple events in negative ways will help lessen the emotional strain on both of you.

CARE FOR THE CAREGIVER

Many people want to care for someone they love when they become ill. Some people are afraid that they will do the wrong thing at the wrong time. Some people expect themselves to do too much; other people feel guilty that they are not doing enough. Only you can decide what you can do, how much time you have to offer, and when.

It is important to take care of yourself while you take care of your loved one. There are things you can learn to help you cope. There are also professional and volunteer caregivers you can ask for information and direct support for yourself. Your local AIDS agency will be able to refer you to them.

Couples and HIV

In many couples, one person is infected with HIV and the other is not. The HIV-negative partner is often the primary caregiver once the infected partner becomes ill. Being in the home on a daily basis, having an emotional tie with one another, and now dealing with the added tasks of caregiving for someone who is seriously ill can all become too much to bear.

There are counseling programs for couples in just this situation. Support groups have formed specifically for couples with 'mixed' antibody status. Joining this type of program early on helps greatly to prepare for the difficulties ahead. Recognizing the need for such support is the first step. The extended family can help by encouraging couples to seek out professional support.

If You Have HIV

Many people who find themselves in a caregiving role are also affected by this illness. You may be HIV-positive or have full-blown AIDS. Your stress level will increase dramatically by having to deal with someone else's failing health or by your own health status. You may have to limit how much time and energy you give to protect your own well-being. Careful planning and the use of community resources will be very important in providing quality care for yourself and your loved one.

Emotional Stress

For the caregiver, fear of not knowing what to do to help is someone with dementia compounded by the fear of loss of the person to a fatal infection. Your feelings of grief, anxiety, and uncertainty about the future can be overwhelming.

Along with these emotional concerns you also have the additional burden of trying to be available, organized and sympathetic to someone who is ill. If you are also infected with HIV, you will need a strong support system of your own. You may want to develop a relationship with an emotional counselor or join a support group to maintain your own sense of well-being.

Some people feel selfish if they spend a lot of time on their own needs while someone they love is very ill. But many people who become overwhelmed by emotional stress also become unable to provide care. Building a life away from AIDS is very important. Taking care of yourself ensures that you will be able to provide compassionate care over a longer period of time.

There are several methods of self-care that you can use to reduce stress. For many people, this may simply be getting out for a walk, or a time of meditation in a place of worship. Being in nature is soothing to many. Whatever setting you choose, giving yourself the opportunity to let go, to leave the responsibilities of caregiving for a few hours or days a week is essential.

Get plenty of exercise. This may be some form of athletics, aerobics or simple walks in the neighborhood. Exercise clears the mind and helps the body release emotional tension. It stimulates the brain and nervous system in beneficial ways to reduce stress.

Emotional stress, erratic sleeping patterns and the physical exertion of caregiving all place greater demands on the body and mind. Giving our body what it needs to perform the extra work of caregiving is essential. It is important to choose whole foods: meat or soy products (vegetarian sources of protein), whole grains, lots of vegetables, especially leafy, dark green and yellow vegetables, dairy products, fresh fruit and nuts.

You can learn more about stress reduction techniques in the holistic health section of your local book or health food store.

LEGAL SAFEGUARDS

Because a person with dementia may not be able to make decisions in the future, there are specific steps that should be taken to protect him and to ensure that the people who most care about his welfare will be able to carry out his wishes. Taking the time to consider these concerns now will help to alleviate some anxiety about the future. The two areas that need to be addressed are medical and financial.

Durable Powers of Attorney

There are two types of powers of attorney - one is medical, the other is financial. They are called the **Medical Durable Power of Attorney** and the **Financial Durable Power of Attorney**.

If the person with dementia becomes too ill to make decisions on his own behalf, other people can make medical and financial decisions for him. He needs to choose ahead of time who will have this responsibility. This person can be a spouse, family member, or friend. This person does not have to be a lawyer. He does have to fill out forms designating the person responsible and describing what his wishes are, should he become unable to speak for himself.

Once he gives someone his financial power of attorney, that person will handle all his finances, including his checking and savings accounts. This person can then pay all his bills. Whoever is chosen will have access to all his money. The person who holds his Medical Power of Attorney will have to make decisions about medical treatment on his behalf. These decisions should be put in writing ahead of time. These forms are available from your local AIDS legal services project or Bar association.

The Living Will

A **Living Will** is intended for people who are suffering from a terminal illness and want to have their wishes followed if they become unconscious and near death. It tells the doctor not to keep someone alive using any artificial means of life support. Artificial means may include a respirator or feeding tube. He can use a Living Will to ensure that he will die a natural death. It is

not the same as a will that is written to leave his things to other people after death.

The individual must carry a copy of his Living Will at all times. This will ensure that if he has a heart attack or other sudden illness the people who take care of him will know what to do. Give a copy to his regular physician, family members, attorney and other important people. It is important to send a copy to the hospital as well. It lets the paramedic, doctor, hospital and family members know his wishes if he cannot speak for himself. It also frees his lover, spouse, and other family members from making what could be a painful, difficult decision. If different members of the family disagree about what should be done, having a Living Will becomes even more important.

Talk to an attorney or a social worker about a Living Will. The more people who know the desires of the person with dementia, the better.

Wills & Living Trusts

Having dementia or HIV infection is not a death sentence. Thinking about things like a **will** may stir up uncomfortable feelings at first. It will give both of you more peace of mind once it is done. He gets to decide what happens to the things that have been important to him.

A will lets everyone know what he wants to do with everything he owns at the time of his death. He can use a will to decide who will receive his possessions, how any cash will be used, who will take care of a pet, who will become his child's legal guardian, and how his funeral, cremation or memorial service will be done. Depending on how much property he owns, he may be able to write his own will or he may have to work with a lawyer so that his wishes will be followed exactly.

If he does not have a will, the courts will step in to decide, according to state laws, who will receive what. If he has a lover or is not legally married, other members of the family may step in to claim possessions he may have wanted to leave to his lover or other friends. Having a will ensures that what he wants to have happen **will** happen.

Every will must be witnessed by at least two people over 18 who can state that the person with dementia knew what he was doing when he made out his will. The person he leaves in charge of carrying out his will is called an **executor**. Your local AIDS legal services program can help him make out a will or set up a **living trust**.

A living trust protects all his assets from probate costs at the time of death. Probate is a court procedure that all estates worth more than $60,000 must go through. If he does not own a home or a business, or have a great deal of cash or stocks and bonds worth more than $60,000, he probably does not have to worry about probate costs. But if he does own property, or have children whose inheritance he wishes to protect from probate costs, he might want to talk to a lawyer about setting up a living trust.

Probate Conservatorships

Conservatorships are sometimes set up for people who cannot manage their own affairs. Someone is appointed by the court to oversee all matters related to the physical, mental and financial well-being of an individual. This person can be a relative, lover, attorney or friend. Contact your local AIDS legal services project, Bar association or social services department to find out more.

There are challenges ahead, but taking it one day at a time will make the road just a little easier. There are people who can help. Find out what is available in your community.