



**Alzheimer's Disease
International**

Help for caregivers



DEPARTMENT OF SOCIAL CHANGE AND MENTAL HEALTH

WORLD HEALTH ORGANIZATION

GENEVA

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This document gives information on dementia in a simple way to families and the public at large. It presents useful and concrete information on how to cope with the disease, and on how to set up self help and mutual support activities for families with a member affected by dementia. It was produced with the cooperation of members of Alzheimer's Disease International.

Key words: Alzheimer's disease, dementia, family support groups, community support, self help groups.



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This booklet aims to help those faced with caring for a person with dementia. It offers information to carers to help them in their challenging task.

Carers who are well informed can help make life better for both themselves and the person with dementia.

This booklet uses the word carer throughout. A carer can refer to a spouse, family member or health professional caring for a person with dementia.

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Foreword

This booklet has been produced by family self-help groups around the world – from both developed and developing countries. It has been put together by Alzheimer's Disease International, a non-profit-making, non-governmental organisation in working relations with WHO, to whom we are most grateful. It brings together the very germane and cogent views of those who live through the experiences of having a family member affected by dementia.

Most of those who contributed to it are relatives - children, spouses and siblings - of people with dementia, with a long and lively experience of dealing with the condition. We hope that in presenting their views and experiences we are contributing to decreasing many people's sufferings and hardships.

As far as coverage of the content is concerned, although it was primarily written by family members with direct experience, some outstanding professionals have also contributed to it. The presentation of this information was determined by families' experience and is certainly different from a scientific journal publication. Nevertheless, it represents an invaluable contribution to the public health perspective.

The following people contributed to this publication; Mr Brian Moss (Australia), Dr Nori Graham (UK), Mrs Franceska Jordan (Australia), Miss A Shirar, and Mrs Rachel Billington (USA).

An important point, however, refers to the cultural background behind this text. Despite every effort to include the experience and viewpoints from people from developing countries, it predominantly reflects a specific socio-cultural economic environment. Whether and how the ideas expressed here will work in regions or countries with quite distinct beliefs, social structures, health care systems and socio-economic models remains to be seen. It is anticipated that the basic ideas will remain valid even if local adaptations are needed.

This publication is intended to stimulate other organisations and groups to produce similar manuals or to make adaptations and translations into their local languages. Those wishing to do so are welcome to contact ADI at the address given on the back page. Also welcome are comments on this publication as well as additional suggestions and reports on experience.

This publication is now being made available to all WHO Member States, NGOs and the public in general. It is our hope it will be disseminated and put at the disposal of those most concerned and in greatest need.

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Basic information about dementia

What is dementia?

Dementia occurs as a result of a disease process. It is a term used to describe different brain disorders that have in common loss of brain function which is usually progressive and eventually severe. Dementia affects memory, thinking, behaviour and emotion.

Dementia affects all groups in society and is not linked with social class, gender, ethnic group or geographical location. Although dementia is more common among older people, younger people can also be affected.

What causes dementia?

Dementia is caused by a number of diseases which produce changes in the brain resulting in the ultimate loss of nerve cells (neurons). These diseases include:

Alzheimer's disease

This is the most common cause of dementia and accounts for 50% – 60% of all cases of dementia. It destroys brain cells and nerves disrupting the transmitters which carry messages in the brain, particularly those responsible for storing memories.

Vascular dementia

The brain relies on a network of vessels to bring it oxygen-bearing blood. If the oxygen supply to the brain fails, brain cells are likely to die and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes.

Dementia with Lewy bodies

This form of dementia gets its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Memory, concentration and language skills are affected.

Fronto-temporal dementia (including Pick's disease)

In fronto-temporal dementia, damage is usually focused in the front part of the brain. Personality and behaviour are initially more affected than memory.

Rarer causes of dementia

There are many other rarer causes of dementia, including progressive supranuclear palsy, Korsakoff's syndrome, Binswanger's disease, HIV and Creutzfeldt-Jakob disease (CJD). People with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease can also be at an increased risk of developing dementia.

What are the symptoms of dementia?

Dementia is a progressive condition. This means that the structure and chemistry of the brain become increasingly damaged over time. The person's ability to remember, understand, communicate and reason gradually declines. How quickly dementia progresses depends on the individual. Each person is unique and experiences dementia in their own way.

The way people experience dementia depends on many factors, including physical make-up, emotional resilience and the support available to them. Viewing dementia as a series of stages can be a useful way to understand the illness, but it is important to realise that this only provides a rough guide to the progress of the condition and not all people will display all of these symptoms.

Some of these symptoms may appear in any of the stages, for example a behaviour listed in the late stage may occur in the middle stage. Also, carers should be aware that in all stages, short, lucid periods can occur.

The following outlines the characteristics of early, middle and late stage Alzheimer's disease, and briefly looks at other dementias.

Alzheimer's disease

Early stage

The early stage is often overlooked and incorrectly labelled by professionals, relatives and friends as 'old age' or a normal part of the

process of ageing. Because the onset of the disease is gradual, it is difficult to identify the exact time it begins. The person may:

- Show difficulties with language
- Experience significant memory loss – especially short-term
- Be disoriented in time
- Become lost in familiar places
- Display difficulty in making decisions
- Lack initiative and motivation
- Show signs of depression and aggression
- Show a loss of interest in hobbies and activities

Middle stage

As the disease progresses, problems become more evident and restricting. The person with dementia has difficulty with day-to-day living, and:

- May become very forgetful – especially of recent events and people's names
- Can no longer manage to live alone without problems
- Is unable to cook, clean or shop
- May become extremely dependent
- Needs assistance with personal hygiene, ie toilet, washing, and dressing
- Has increased difficulty with speech
- Shows problems with wandering and other behavioural abnormalities
- Becomes lost at home and in the community
- May experience hallucinations

Late stage

This stage is one of total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious. The person may:

- Have difficulty eating
- Not recognise relatives, friends, and familiar objects
- Have difficulty understanding and interpreting events
- Be unable to find their way around in the home
- Have difficulty walking
- Have bladder and bowel incontinence
- Display inappropriate behaviour in public
- Be confined to a wheel chair or bed

Vascular dementia

Some people with vascular dementia find that symptoms remain steady for a time and then suddenly decline as the result of another stroke. This contrasts with the gradual decline many people with Alzheimer's disease experience. It is sometimes difficult to determine whether people have Alzheimer's or vascular dementia. It is also possible to be affected by both.

Fronto-temporal lobe dementia (including Pick's disease)

During the early stages the memory may be unaffected. However, there may be other changes. For example, the person may seem more selfish and unfeeling. They may behave rudely, or may seem more easily distracted. Other symptoms may include loss of inhibition, ritualised behaviour and a liking for sweet foods. In later stages the symptoms are more similar to those experienced in Alzheimer's disease.

Dementia with Lewy bodies

Half or more of those affected also develop signs and symptoms of Parkinson's disease such as slowness of movement, stiffness and tremor. They may also have difficulty in judging distances and are more prone to falls. People with this dementia also commonly experience visual hallucinations. One feature of this dementia which often puzzles carers is that the abilities of the affected person often fluctuate.

Why is diagnosis important?

It is important to get a proper diagnosis of dementia. A diagnosis is essential to:

- Rule out other conditions that may have symptoms similar to dementia and that may be treatable. These include depression, chest and urinary infections, severe constipation, vitamin and thyroid deficiencies and brain tumours.
- Access advice, information and support.
- Allow the person with dementia and carer to prepare and plan for the future.

Identifying the cause of dementia is becoming increasingly important as drugs for treating different dementias become available.

There is no simple test to make a diagnosis. Making a diagnosis of dementia is often difficult, particularly in the early stages. A diagnosis is made by taking a careful history of the person's problem from a close relative or friend, together with an examination of the person's physical and mental status.

Are there treatments for dementia?

At the moment there is no curative treatment for dementia, although many of the problems associated with dementia such as restlessness and depression can be treated. However, there is a great deal that can be done for the person with dementia as well as things to ease the burden on you, the carer. Consult your physician, social worker or other health professional for more information.

There are some drugs available for people with mild to moderate Alzheimer's disease. These drugs are not a cure but may temporarily slow down the progression of symptoms of Alzheimer's disease in some people. Contact your nearest Alzheimer association or physician for more information.

Living with and caring for a person with dementia

Caring can be very difficult at times. However, there are ways to deal with the situation. Here are some tips that have worked for other carers:

Establish routines but keep things normal

A routine can decrease the decisions you will need to make and bring order and structure into an otherwise confused daily life. A routine may come to represent security for the person with dementia. Although a routine can be helpful, it is important to keep things as normal as possible. As much as their changing condition will allow, try to treat the person as you did before the disease.

Support the person's independence

It is necessary that the person remains independent as long as possible. It helps to maintain self respect and decreases the burden on you.

Help the person maintain dignity

Remember that the person you care for is still an individual with feelings. What you and others say and do can be disturbing. Avoid talking about

the person's condition in their presence without involving them in the conversation.

Avoid confrontation

Any type of conflict causes unnecessary stress on you and the person with dementia. Avoid drawing attention to failure and maintain a calm composure. Becoming upset can only make the situation worse. Remember it is the disease, not the person's fault.

Simplify tasks

Try to make things simple for the person with dementia. Don't offer too many choices. For example, in the early stages of the disease, the person may be able to dress themselves but as the disease progresses you will need to guide them and, eventually, clothe the person yourself.

Maintain a sense of humour

Laugh with the person with dementia. Humour can be a great stress reliever.

Make safety important

Loss of physical coordination and memory increases the chance of injury, so you should make your home as safe as possible.

Encourage fitness and health

In many cases, this can help maintain the person's existing physical and mental abilities for a time. The appropriate exercise depends on the person's condition. Consult your physician for advice.

Help make the best of a person's existing abilities

Planned activities can enhance a person's sense of dignity and self-worth by giving purpose and meaning to life. A person who was once a homemaker, gardener, doctor or business executive may gain satisfaction from maintaining abilities related to their previous profession. Remember, however, that because dementia is progressive, the person's likes, dislikes and abilities may change over time. This will require you, the carer to be observant and flexible in planning activities.

Maintain communication

As the disease progresses, communication between you and the person can become more difficult. It may be helpful if you:

- Make sure the person's senses are not impaired, such as eyesight and hearing (eg spectacles may no longer be of the right prescription, or a hearing aid may not be functioning properly)
- Speak clearly, slowly, face to face and at eye level
- Show love and warmth by showing affection if this is comfortable for the person
- Pay attention to the person's body language – people whose language is impaired communicate through non-verbal means
- Be aware of your own body language
- Find out what combination of word reminders, or prompting words, guidance and demonstration is needed to communicate effectively with the person
- Make sure you have the person's attention before speaking

Use memory aids

In the early stages of dementia, memory aids can help the person to remember, and they can help prevent confusion. The following are successful examples:

- Display large clearly-labelled pictures of relatives so the person can keep track of who is who
- Label doors of rooms with words and bright distinctive colours

Memory aids will not be so useful in the later stages of dementia

Practical tips on managing dementia

The following suggestions are taken from the experiences of carers. You may find some difficult to carry out. Remember, nobody is perfect. You the carer can only do your best.

Bathing and personal hygiene

The person with dementia may forget to bathe, or no longer recognise the need, or may have forgotten what to do. In this situation it is important to respect the person's dignity when offering to help.

Suggestions:

- Maintain the person's former routine for washing as much as possible
- Try to make bathing a pleasant and relaxing occasion
- A shower may be easier than a bath but if the person has not been used to a shower it may seem alarming
- Simplify the task as much as possible
- If the person refuses to bathe, try again a little later, when the mood may have changed
- Check if teeth are being cleaned regularly
- Allow the person to do as much as possible unaided
- If the person appears embarrassed, keeping portions of the body covered while bathing may be helpful
- Think about safety. Something firm to hold on to, such as support rails, a non-slip mat or an extra chair all help
- If bathing always leads to conflict, a stand-up wash might be better
- If you constantly have problems helping with this, get someone else to do it

Dressing

The person with dementia will often forget how to dress and may not recognise the need to change clothes. People with dementia sometimes appear in public with inappropriate clothing.

Suggestions:

- Lay out clothes in the order they are to be put on
- Avoid clothes with complicated fastenings
- Encourage independence in dressing as long as possible
- Use repetition if necessary
- Use non-skid rubber-soled shoes

Toileting and incontinence

The person with dementia may lose the ability to recognise when to go to the toilet, where the toilet is or what to do when in the toilet.

Suggestions:

- Create a schedule for going to the toilet
- Make the toilet door more obvious by using bright colours and large letters
- Leave the toilet door open so it is easy to find
- Make sure clothing can be easily removed
- Limit drinks within reason before bed time
- Providing a chamber pot or commode by the bedside may be helpful
- Get professional advice

Cooking

For the person with dementia, the ability to cook may be lost in the middle stages. This poses severe problems if the person lives alone, with an increased risk of injury. Poor physical coordination can lead to burns and cuts.

Suggestions:

- Assess how well the person can do their own cooking
- Enjoy cooking as a shared activity
- Install safety devices, for example change from gas to electricity
- Remove sharp utensils
- Provide meals, or meal service, and try to see that enough nutritious food is eaten

Eating

People with dementia often forget if they have eaten, or how to use utensils. In the later stages of dementia the person may need to be fed. Some physical problems will arise such as not being able to chew properly or swallow.

Suggestions:

- You may have to remind the person how to eat
- Use finger food – it can be easier to manage and not as messy
- Cut up food in small pieces to prevent choking. In the late stages of the disease, it may be necessary to mash or liquidise all food
- Remind the person to eat slowly
- Be aware that the person may not be able to sense hot or cold, and may burn their mouth on hot foods or liquids
- When the person has difficulty swallowing, consult your physician to learn a technique to stimulate swallowing
- Serve one portion of food at a time

Driving

It could be dangerous for the person with dementia to drive, since judgment is impaired and reactions are slowed.

Suggestions:

- Discuss the subject with the person gently
- Suggest using public transportation, as appropriate
- If you cannot dissuade the person from driving, it may be necessary to consult with your doctor or the driver's licensing authority

Alcohol and cigarettes

There is no problem with the person with dementia drinking alcohol in moderation, if it does not cause complications with medication. Cigarettes introduce a greater danger because of the risk of fire and damage to health.

Suggestions:

- Supervise the person when smoking; or discourage smoking altogether – perhaps with a physician's prescription
- Check alcohol and medication with your doctor

Difficulty sleeping

The person with dementia may be restless at night and disturb the family. This can be your most exhausting problem as a carer.

Suggestions:

- Try to discourage sleeping during the day
- Try daily long walks, and add more physical activity during the day
- Try to make the person as comfortable as possible at bed time

Repetitive behaviour

A person with dementia may forget what they have said from one moment to the next, leading to repetitive questioning and actions

Suggestions:

- Try to distract the person with dementia, offering something else to see, hear or do
- Write down the answer to commonly asked questions
- Give hugs and reassure with affection, if appropriate for the person

Clinging

The person with dementia may become extremely dependent on you and follow you everywhere. This can be frustrating, difficult to handle, and rob you of your privacy. The person may act this way as a result of feeling insecure and fear that when you leave, you will not return.

Suggestions:

- Provide something to occupy his/her attention while you step away
- You may want to call on a sitter to give yourself some privacy

Losing things and accusations of theft

The person with dementia may often forget where objects were placed. In some cases they will accuse you and others of taking missing objects. These behaviours are caused by insecurity combined with a sense of loss of control and of memory.

Suggestions:

- Discover if the person has a favourite hiding place
- Keep replacements of important items, eg keys
- Check waste baskets before emptying them
- Respond to the person's accusations gently – not defensively
- Agree with the person that the item is lost and help find it

Delusions and hallucinations

It is not uncommon for the person with dementia to experience delusions and hallucinations. A delusion is a fixed false belief. For example, the person may hold the false belief of being under threat of harm from the carer. To the person with dementia the delusion is very real and causes fear, and may result in distressing self-protective behaviours.

If the person is experiencing an hallucination, he/she might see or hear things that are not there; for instance, figures at the foot of the bed, or people talking in the room.

Suggestions:

- Do not argue with the person about the validity of what was seen or heard
- When the person is frightened try to give comfort. Your calm voice and gently holding a hand can be comforting
- Distract the person by drawing attention to something real in the room
- Check with your doctor about medications that are being used, these may contribute to the problem

Sexual relationships

Alzheimer's disease does not usually affect sexual relationships, but the person's attitude may alter. Gentle cuddling and holding may be mutually satisfying, and will let you know if the person is able or inclined to engage in further intimacy. It is wise to be patient. The person may not respond in the same way as before, or may seem to lose interest. For some couples, sexual intimacy continues to be a satisfying part of their relationship.

The opposite may occur, too. The person may make excessive demands for sex, or behave in a manner that makes you feel uncomfortable. You may feel guilty about needing or wanting to sleep separately.

Suggestions:

- Seek help from other carers or professionals you trust
- In some countries there are people with special skills in this area, such as psychologists, social workers or counsellors who can provide advice and guidance
- Don't be afraid to discuss these and related issues with a professional who is trained to understand and help you manage them

Inappropriate sexual behaviour

The person with dementia may display inappropriate sexual behaviour, but it is rare. Behaviour may include undressing in public, fondling the genitals, or touching someone in an inappropriate way.

Suggestions:

- Try not to over-react to the behaviour – remember it is the disease taking effect
- Try to distract the person to another activity
- If the person removes clothing, gently discourage the behaviour, and try to distract the person
- If it persists and is troubling, seek help from a professional

Wandering

This can be a worrying problem which you may need to manage. People with dementia may wander around the home or leave the house and wander around the neighbourhood. They may get lost. Safety is a primary concern when the person with dementia is out in public alone.

Suggestions:

- Make sure the person carries some form of identification
- Make sure your home is secure and that the person is safe in your home and cannot leave without your knowing
- When the person is found, avoid showing anger – speak calmly, with acceptance and love
- It is helpful to keep an up-to-date photograph in case the person gets lost and you must ask for help from others

Violence and aggression

From time to time, the person may become angry, aggressive or violent. This can happen for a variety of reasons such as sense of loss of social control and judgment, loss of the ability to express negative feelings safely, and loss of the ability to understand the actions and abilities of others. This is one of the most difficult things to cope with as a carer.

Suggestions:

- Keep calm, try not to show fear or alarm
- Try to draw the person's attention to a calming activity
- Give the person more space
- Find out what caused the reaction – and try to avoid it in the future
- If violence occurs often, you will need to seek help. Talk to someone for support, and speak with your doctor about help in managing the person

Depression and anxiety

The person with dementia may experience depression and be withdrawn and unhappy, and will speak, act and think slowly. This can affect the daily routine and interest in food.

Suggestions:

- Speak with your doctor, who may be able to help or offer a referral to a counsellor, psychologist or psychiatrist
- Give more love and support to the person
- Don't expect the person to snap out of the depression

The personal and emotional stress of caring

Dementia not only affects the person with dementia, it affects the entire family. The greatest burden is placed on you, the carer. The personal and emotional stresses of caring for a person with dementia are enormous and you need to plan ways of coping with the disease for the future. Understanding your emotions will help you successfully cope with the person's problems as well as your own. Some of the emotions that you may experience include grief, guilt, anger, embarrassment and loneliness.

Grief

This is a natural response for someone who has experienced a loss. Because of dementia you may feel that you have lost a companion, friend, or parent, and grieve for the way the person used to be. Just when you think you have adjusted, the person changes again. It maybe devastating when the person no longer recognises you. Many carers have found that joining a support group is the best way to get help to keep going.

Guilt

It is common to feel guilty for being embarrassed at the person's behaviour, for feeling anger at the person, or for feeling that you cannot carry on. You might be feeling guilty about considering placing the person in a nursing home. You may find it helpful to talk to other carers and friends about the feelings.

Anger

Your anger may be mixed. It may be directed at the person, yourself, the doctor or the situation, all depending on the circumstances. It is important to distinguish between your anger at the person's behaviour – which is a result of the disease – and your anger with the person. Seek advice from friends, family, or a support group. Sometimes people feel so angry that they are in danger of hurting the person they care for. If you feel like this, you must seek professional help.

You may find yourself taking on the person's responsibilities, such as paying the bills, housekeeping, cooking. This increase of responsibilities can be very stressful. It may be helpful to talk over your feelings with other family members or a professional.

Embarrassment

You may feel embarrassed when the person displays inappropriate behaviour in public. The embarrassment may fade if you share these feelings with other carers who are experiencing similar occurrences. It also helps to give explanations about the illness to friends and neighbours, so that they will better understand the person's behaviours.

Loneliness

Many carers withdraw from society and are confined in and around their homes with the person with dementia. Being a carer can be lonely – you may have lost companionship with the person and lost other social contacts due to the demands of being a carer. Loneliness makes it hard to cope with the problems of caring. It is helpful to make it a priority to maintain friendships and keep social contacts.

Caring for yourself

Family

For some carers the family is the greatest source of help. For others the family is the biggest source of distress. It is important to accept help from other members of the family if they are available and not to carry the whole burden of caring on your own. If you are feeling distressed because your family members are not helping, or are perhaps even critical of you as a carer, it may be helpful to call a family meeting to discuss the care of the person. Such behaviour may be down to a lack of understanding about dementia.

Share your problems

You need to share your feelings about your caring experiences with others. If you keep them to yourself, it may be more difficult for you to look after the person with dementia. If you can realise that what you are experiencing is a natural response to your situation, it will be easier for you to cope. Try to accept support when it is offered by others, even if you feel you are troubling them. Try to think ahead and have someone to turn to in an emergency.

Make time for yourself

It is essential that you make time for yourself. This will allow you to spend time with others, enjoy your favourite hobbies and, most important, enjoy yourself. If you need a longer amount of time away, try to find someone to take over the caring for you so that you can have a rest.

Know your limits

How much can you take before it becomes too much? Most people will come to realise how much they can take before they reach the point where the caring becomes too demanding. If your situation is too much to bear, take action by calling for help to prevent and avoid a crisis.

Don't blame yourself

Do not blame yourself or the person with dementia for the problems you encounter. Remember, the disease is the cause. If you feel your relationships with friends and family are dwindling away, don't blame them or yourself. Try to find what is causing the breakdown and discuss it with them. Remember that relationships with others can be a valuable source

of support for you. This can prove to be an asset for both you and the person with dementia.

Take and seek advice

It will help you to seek advice concerning your changing role and the changes that occur in the person with dementia.

Remember you are important

You are important to yourself. And you are an important person in the life of the person with dementia. Without you the person would be lost. This is another reason why it is so essential to take care of yourself.

Help for you, the carer

Learning to accept help may be new to you. However, as is often the case, members of your family, friends or neighbours may want to do something to help you and the person with dementia. But, they may not know what might be helpful or welcomed by you. A word or suggestion from you and perhaps some guidance will allow them an opportunity to help. This may help someone else feel useful, help the person with dementia, and provide you with some welcome relief as well.

A self help group (a group for carers) can be another source of help for you. A self help group (also called a support group) provides an opportunity for carers to come together, share their problems and solutions, and support each other. In a growing number of countries there are Alzheimer's associations that can help you find such a carers' group. If no such association exists you could consider establishing one.

Additionally, to support you in your care giving role, it is useful to know about any medical, practical, personal, or financial help that may be available where you live. Your physician, a nurse or a social worker may be able to help you identify and refer you to the resources you need.

From country to country, there is wide variation in medical and social care for people with dementia and their carers. However, wherever you live, there are some basic things that carers need. These are:

- Medical help with diagnosis and care
- Help with the practical tasks of caring
- Rests (breaks) from caring
- Regular health checks for you the carer
- In-home care, a day centre, or nursing home care
- Information

Alzheimer's Disease International

A source of help for you

Alzheimer's Disease International (ADI) is the worldwide federation of Alzheimer associations around the world. These associations represent people with dementia and their families. These Alzheimer associations offer information and help to people with dementia and their carers within their countries.

In each country, the member association works to develop support groups and educational programmes for affected families and the general public. Each has a medical and scientific component. Some members also provide counselling, day centres, home care, and other types of respite care programmes.

You can contact ADI for:

- More information about dementia
- Details of the Alzheimer association nearest to you
- Guidance in developing an Alzheimer association in your country

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