



**Alzheimer's Disease
International**

Alzheimer's Disease 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

预览已结束，完整报告链接和二维码如下：

https://www.yunbaogao.cn/report/index/report?reportId=5_29847

