



Alzheimer's Disease International

World Alzheimer's Day Bulletin

21 September 2000

Dementia; challenge to quality of life

In just 25 years, 34 million people will have dementia. This figure gains significance when it is put in the context of increasing life expectancy and an ageing population in developing countries. Already 66% of people with dementia live in developing countries but by 2025 this will rise to nearly 75%.

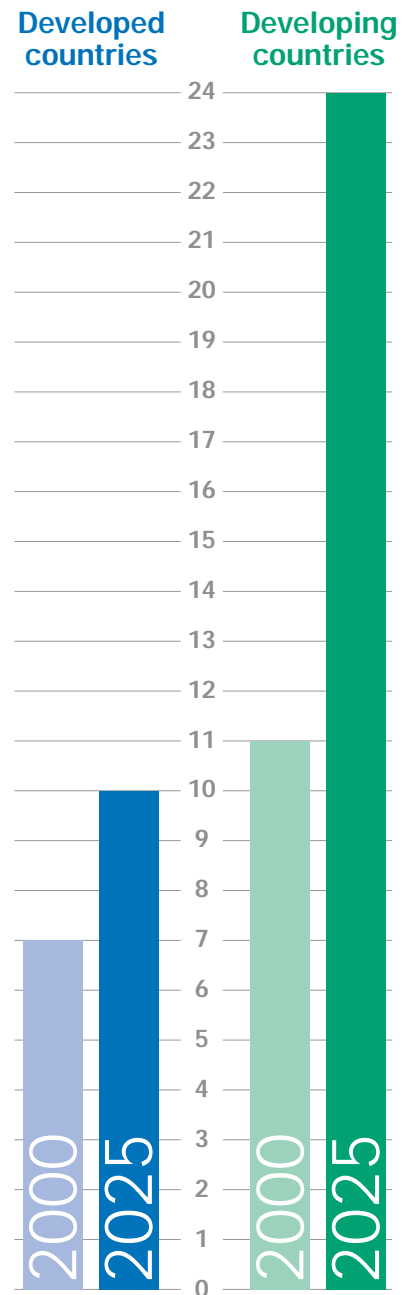
More than half of the people with dementia have Alzheimer's disease. Alzheimer's disease is a

progressive brain disorder that causes memory loss, behaviour and personality changes. Age is the most significant risk factor for developing dementia, which affects 1 in 20 people over the age of 65.

As the memory, thinking and judgement of someone with dementia becomes increasingly impaired, they will need someone to help them with all aspects of daily living. Despite this

loss of capacity, a person with dementia continues to be a person of worth and dignity, deserving of the same respect as any other person. There is currently no cure for dementia but we can help people with dementia live as good a life as possible. Carers and health care professionals have a crucial role to play in sustaining the quality of life of a person with dementia.

Millions with dementia



Projected increase in numbers of people with dementia for the years 2000 – 2025
Totals for all countries: 2000 18 million 2025 34 million

Greetings from WHO on World Alzheimer's Day

No one can ignore the problem of ageing and the increasing number of people with dementia, which accompanies the ageing of populations. WHO recognises that Alzheimer's disease and other types of dementia represent a major health problem in all countries. There are an estimated 18 million people with dementia worldwide.

These are conditions for which family members take the main responsibility as direct care givers. However, caring for people with dementia usually involves other people. The lives of a vast number of people are directly or indirectly affected by dementia. Governments in all countries need to recognise the part that carers play. Efforts must be made to improve services for patients as well as to provide financial and other types of support to assist carers in their task.

On this day, National Alzheimer Associations all over the world organise activities to bring this problem to the attention of their governments and the general public. Alzheimer's Associations do a great deal to provide information and assist carers in their tasks. On behalf of WHO I salute their endeavours.

Gro Harlem Brundtland MD MPH
Director-General, World Health Organization

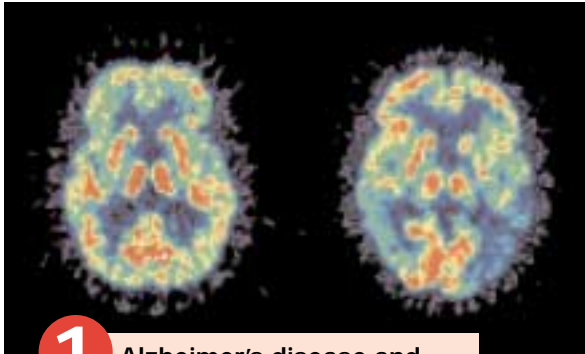




**Alzheimer's Disease
International**

In 1999, ADI launched its charter of principles for the care of people with dementia and their carers, prepared with help from ADI members around the world. Taking account of these principles can guide carers and health professionals in meeting the needs of people with dementia and maintaining their quality of life. The principles also focus on the needs of carers, which must be addressed so they are able to maintain their own quality of life and care for the person with dementia.

Charter of



1

Alzheimer's disease and related dementias are progressive, incapacitating diseases of the brain that have a profound impact on persons with dementia and members of their families.



2

A person with dementia continues to be a person of worth and dignity, and deserving the same respect as any other human being.

THE STAR, MALAYSIA

People with dementia should as far as possible participate in decisions affecting their daily lives and future care.

5



DANIEL J SPLAINE, PLUM ISLAND PHOTOGRAPHICS



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The family carers of a person with dementia should have their needs relating to the care assessed and provided for and should be enabled to take an active role in this process.

Alzheimer's Disease International recognises the following principles as fundamental to the provision of care for people with dementia and for the support of their family members and carers

principles



3 People with dementia need a physically safe living environment and protection from exploitation and abuse of person and property.



7 Adequate resources should be available and promoted to support people with dementia and their carers throughout the course of the disease.



4 People with dementia require information and access to coordinated medical and welfare services. Anyone thought to have the disease needs medical assessment and those with the disease require ongoing care and treatment.



8 Information, education and training on the disease, its effects and how to provide care must be available to all those involved in the assistance of people with dementia.

Quality of life



The concept of 'quality of life' has gained widespread use in the health care sector over recent years. People with dementia experience declining cognitive abilities which cannot be reversed. Even so, there is much that can be done to maintain and improve their quality of life.

What is quality of life?

According to the World Health Organization 'Health is a state of complete mental, physical and social wellbeing, and not merely the absence of infirmity.'

Quality of life is a much broader concept than either health or disease. It is rather difficult to define as everyone has their own ideas. 'Complete mental, physical and social wellbeing' is certainly one aspect but there are others. We would like to hear yours.

What are the key elements of quality of life?

Although each person has their own views on quality of life, here are some key elements that are common to many people:

- Getting around
- Social relations
- Affording and obtaining the things you need
- Living independently
- Understanding the world around you
- Occupying yourself

What influences quality of life?

The person with dementia

- Living circumstances
- Support network of family and friends
- Family relationships before and after illness
- The personalities of those involved
- Care received
- Financial resources

The state

- International conventions
- Health policy
- Welfare and benefits
- Responsibility for long-term care (state vs. family)
- National dementia awareness (role of Alzheimer association, media, government)

Quality of life

The local community

- Awareness of dementia in the local community
- Positive and negative attitudes (stigma)
- Neighbourliness
- Health and social services
- Transport and the built environment
- Support groups and voluntary services

Alzheimer's Disease International would like to thank Dr Martin Prince and Dr Sube Banerjee both of the Institute of Psychiatry, London, UK for their help in preparing this article.

What does quality of life add to clinical assessments of dementia?

Quality of life assessments add an important and often neglected set of dimensions to clinical assessments:

Holistic – emphasises the person as a whole rather than the disease

Personal – focuses on the effects on the person with dementia rather than on family carers, health services, or national finances

Comprehensive – includes the whole range of human activity and interest

Positive – judged more in terms of the presence of good things in a person's life rather than the lack of bad things (like disease)

Subjective – takes account of how people feel rather than how they behave.

For example:

A clinical assessment might include

Cognitive function	Behavioural disturbance
Depression	Wandering
Physical health	Aggression
	Sleep disturbance
	Apathy
	Social withdrawal

A quality of life assessment might include

Comfort and relaxation	Sense of wellbeing
Self-esteem	Satisfaction with daily activities
Interests	Sources of pleasure
Self-expression	Companionship
Independence	

Quality of life assessments can be used, together with clinical assessments:

- In research, to help decide which treatments and interventions work, and which offer the best value for money
- In clinical practice, to assess individuals and their needs

How can quality of life in dementia be enhanced?

Governments, local communities, people with dementia and their carers all have a part to play in enhancing quality of life in dementia. For example, governments can be lobbied to provide a fair level of financial support for people with dementia and their carers. Community health workers can learn new skills in dementia training programs. A person newly diagnosed with dementia and his family might benefit from an information booklet. Alzheimer associations work at each of these levels, raising awareness about dementia and what support there is available.

A person with dementia continues to be a person of worth and dignity and it is always important to remember this.

Feedback

We would welcome your comments to any of the questions raised in this bulletin. Please contact us at Alzheimer's Disease International 45/46 Lower Marsh, London SE1 7RG, UK adi@alz.co.uk www.alz.co.uk