

ADI was founded in 1984 and has grown into an umbrella organisation of 43 national Alzheimer associations. ADI is in official relations with the World Health Organization.

ADI aims to:

- Support members in their activities and encourage new Alzheimer associations
- Disseminate information
- Support an annual conference focussed on carers and carer organisations
- Collaborate with other international organisations with similar interests
- Encourage research
- Raise public and political awareness at national and international level

Alzheimer's Disease International
45/46 Lower Marsh
London SE1 7RG, United Kingdom
Telephone + 44 171 620 3011
Fax + 44 171 401 7351
Email: adi@alz.co.uk Web: www.alz.co.uk
or contact your local Alzheimer's association



Making life easier for carers

Most people with dementia are cared for by a member of their family. But who looks after the carer? In this article we describe some of the findings of research into the ways of easing the stress on carers

RESEARCH INTO CARING

Throughout the world family members are the backbone of care for people with dementia. Most family members very much want to care for their loved ones but many find it difficult. As the disease progresses carers find themselves increasingly responsible for basic care such as dressing, bathing and tending to toilet needs. If the carer has not already retired, as many have, they may find it difficult to combine employment with their caring responsibilities. In addition their own social life and enjoyment of leisure may be limited, though for many such restrictions are willingly accepted. However, carers often report lack of support and assistance from other family members, as well as health and social care professionals. As a result some carers show physical and mental health problems arising from stress. Research and experience show that there are ways of reducing these stresses.

INFORMATION AND EDUCATION

Information empowers carers. Carers need to know about the disease, how it progresses and how to deal with the many different problems as they arise. Initially information will be given by a professional following a thorough assessment leading to a diagnosis and a review of needs. After this, while professionals will do their best, they often do not have the time to answer questions. Alzheimer associations play an invaluable part here providing fact sheets, newsletters and helplines.

SUPPORT GROUPS

These are often run by Alzheimer associations. Carers come together to share their experiences and feelings and help each other with practical

ideas to deal with the challenge of caring. Not everyone wants to join a group. But research has shown that those who do find them helpful and experience a reduction in their feelings of depression.

COUNSELLING

Where it is available counselling has been shown to be effective in improving morale and decreasing feelings of stress. When combined with continued support it has been shown to reduce depression in carers. Counselling may be especially necessary when the question of transfer to a nursing home arises. At that time it is common for carers to experience strong feelings of guilt, grief, anger and depression. Counselling can also be helpful during bereavement following death. In some countries training courses have been set up to help carers avoid triggering difficult behaviour and to deal with such behaviour when it occurs. Training courses have been shown to reduce stress and depression.

RESPITE

Respite provides a break from caring. Respite can be achieved informally by arranging for the person with dementia to stay with relatives or for relatives and friends to come into the home to give the main carer a break.

Formal respite services may include day care, home respite care and short stays in residential homes or hospitals. Many carers find having a break indispensable. It enables them to have time for themselves, to go shopping, to see relatives and friends and to attend to their own personal needs. Research has shown that respite care is effective in reducing stress. Carers are often reluctant to use respite services

even when they exist. Carers should be encouraged to do so because they can have positive effects.

PRACTICAL ASSISTANCE

Some carers find the practical aspects of their life really difficult. They may be old and frail themselves and not able to do the routine housework. The heavier side of caring, lifting and dressing may be beyond them. Yet they may very much wish the person for whom they are caring to remain at home. Assistance in the home can be invaluable here. Helpers need to be reliable, regular and consistent – ie involve the same person every time.

A KEY PERSON

It is helpful to have a key person, often a nurse, who can provide support and advice throughout the duration of the dementing illness. If families are well supported they can cope more easily with caring, and the people for whom they are caring often become easier to manage.

CONCLUSION

Carers have unique needs and wishes. Carers are the real experts in what they need. They need to be respected and services should be sufficiently varied and flexible to cater for individual situations. Services should also take into account that needs change as the illness progresses.

Alzheimer associations are uniquely placed to help carers in some of these ways and to press policy makers to fill gaps in services. Research into caring is a key component to ensure that the quality of life of the carer and the person being cared for is maintained at the highest level.

World Alzheimer's Day Bulletin

21 September 1999



Greetings

Princess Yasmin Aga Khan
President of ADI

Greetings from ADI on World Alzheimer's Day. ADI recognises that Alzheimer's disease and related dementias represent a major health issue in all countries. These are conditions for which family members take the main responsibility. There are estimated to be 18 million people with dementia in the world and for each of these there is at least one carer and often many more. The lives of a vast number of people are affected by dementia.

Governments in all countries need to recognise the part that carers play. Governments need to provide finance and support services to assist carers in their task. No government can ignore the problem of ageing. An increasing number of people with dementia is an inevitable consequence of the ageing of populations.

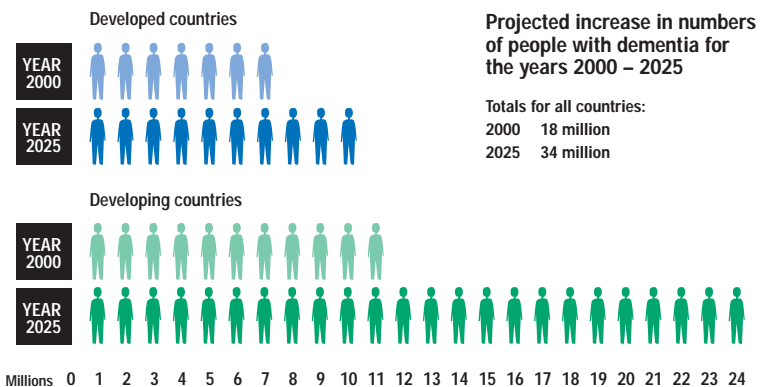
On this day, national Alzheimer associations all over the world organise many activities to bring the challenge of dementia to the attention of their governments and the general public. Alzheimer associations do a great deal to provide information and assist carers in fulfilling their role. On behalf of ADI, I salute their endeavours.



Carers need greater support as dementia figures grow

The family is the cornerstone of support for people with dementia. As the numbers of people with dementia will increase dramatically over the next 25 years, we must remember the millions of families world wide meeting the day-to-day challenge of caring. No matter where you live in the world, most people with dementia are cared for by their families. As you will read in this bulletin, the support available to carers varies greatly from one part of the world to another. Carers need practical, emotional and financial help. The right support at the right time can make a real difference to a family's ability to care. This support can come from different sources – other members of the family, governments and voluntary organisations such as Alzheimer associations.

- The next 25 years will see a dramatic increase in the numbers of people with dementia
- This increase will be most marked in China, India and Latin America
- Already most people with dementia live in developing countries
- By 2025 over 70% of people with dementia will live in developing countries



1999 – International Year of the Older Person

The developed world became rich before it became old . . .
. . .the developing world is getting older but not richer

There is no cure for dementia and, as yet, no way to stop its progression. Most people who develop dementia will need care. As the memory, thinking and judgement of someone with dementia becomes increasingly impaired, they will need someone to help them with most aspects of daily living. Families usually take responsibility for the care of their loved ones – but they in

turn need support. Supporting the family is an essential part of meeting the challenge of dementia.

There are several factors which influence family care for people with dementia; family living arrangements, government policies for support of the older person, sources of income for older people and their carers and the cost of care. Listening to the experience of carers in

different parts of the world, it is apparent that the support available to people with dementia and their carers varies dramatically.

We must not forget that most people with dementia and their carers live in low to middle income countries. They are likely to have no access to specialist health or social care services and no pension or disability benefits.

What support is there

1: Living arrangements



- Living arrangements tend to vary dramatically throughout the world
- They are often deeply culturally ingrained – Confucian respect for the older person in China and Japan, for example
- In some countries older people typically live in multigenerational households – this is true for 9 out of 10 older people in China and Japan. Although this traditional system is under threat from social and economic change, it is likely to remain for the foreseeable future.
- In other countries it has always been usual for older people to live alone (35% in the UK) or with a spouse (40% in the UK)

2: Alzheimer associations



Alzheimer associations are dedicated to providing support to people with dementia and their families. They provide:

- Practical and emotional help such as helplines and support groups
- Information
- Advocacy to governments
- Training for carers and professionals
- Services such as respite and day care



The family

- The family is the main support for people with dementia
- The family's role is often overlooked in developed countries, with their advanced health and social care systems
- The family's effectiveness is sometimes over estimated in developing countries – older people are often dependent on children for basic living necessities, with no health and social care systems, lack of family support can have catastrophic consequences

re for family carers?

3: Financial support

Most carers are not wealthy and often contribute part of their personal income or savings towards meeting the costs of care.

- Many, but by no means all, developed countries have comprehensive pension schemes and disability benefits for older people. In the UK all men over 65 and women over 60 receive a subsistence pension
- In developing countries very few have even a subsistence pension – less than 5% in Ghana, for example. Many older people continue to work, are dependent on children or rely on charity



The relative costs of different levels of care

4: Government policies

Governments need to recognise the challenges of an ageing population and provide better support services for carers and people with dementia. Many countries have policies for the provision of care and support of the older person. However:

- These policies vary enormously even in one region such as Europe
- In some Scandinavian countries the state has taken upon itself a legal responsibility to provide comprehensive care for older people in need
- At the other end of the spectrum, countries like Spain, Greece and China instead place a legal responsibility on families to provide all care and financial support
- Most countries have policies somewhere between these two extremes
- Other governments encourage the family to care through a system of incentives. In Japan until recently children were legally obliged to care for their elderly parents; nowadays the government stresses the need for families to care and provides tax breaks for carers



The spectrum of national care policies