

Alzheimer's Disease International

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Alzheimer's Disease International (ADI) is the international federation of 75 Alzheimer associations throughout the world and is in official relations with the World Health Organization. ADI was established to raise awareness about dementia, strengthen Alzheimer associations and provide a platform for the exchange of knowledge with the ultimate goal of improving the quality of life of people with dementia and their families.

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By 1980 there were four national associations, in Canada, Australia, the USA and the UK. Their first priorities were providing information to raise awareness and supporting families.

Recognising that Alzheimer's disease does not discriminate in any way and that it presents a health and social care challenge worldwide, representatives of the first Alzheimer associations began to discuss their concerns about the global impact of dementia. In October 1984, the Alzheimer's Association in the USA helped to launch ADI by organising a meeting in Washington, DC, with the support of the World Health Organization, to bring together all the emerging Alzheimer associations around the world at that time. These associations wanted to ensure that families coping with Alzheimer's disease would have access to information and support.

Dementia: the scale of the problem

There are currently 24 million people living with dementia worldwide. The numbers of people affected will rise to 81 million by 2040, 71% of whom will live in low- and middle-income countries. With rapidly ageing populations, the rate of increase in the number of people with dementia is predicted to be three to four times higher in these countries than in their high-income counterparts. ADI has grown into a truly global organisation, with members in every world region. Most members are now in low- and middle-income countries, reflecting the global burden of dementia.

Dementia is a major cause of dependency in older people and yet most low- and middle-income countries have little health or social care resources devoted to it. The resources that are available focus on basic

healthcare needs such as maternal and child health and infectious diseases. However, the health and social needs of the large and rapidly growing numbers of people with dementia should be a matter for concern for policy makers in developing regions.

The need for care

Creating the climate for change is essential to achieving progress in dementia care. Lack of awareness of dementia is one of the key problems. Distorted perceptions lead to dementia being stigmatised and in many countries means that people with dementia and their families are often reluctant to seek much-needed help and support. When they do seek help they are often excluded from residential care and denied access to hospitals.

It is widely believed that extended families care for their own older people in low- and middle-income countries. Research shows that in many places this is not true; with an increase in urbanisation and greater mobility in populations, grown up children often leave their parents. There is a danger that the care of older people will be made a low priority by governments because of these falsely held views about extended families and that those with dementia will be neglected.

National Alzheimer associations are the main source of information and support for people with dementia and their families – in some countries they are the only source. It is because of these associations that people with dementia and their carers have been and are able to exert a powerful voice about their needs. Some associations also provide services, fund research and provide education and training. There is great diversity within ADI's membership, from the large established organisations that founded ADI to the new members such as Iran, Lebanon and China.

ADI aims to achieve its mission of improving the quality of life of people with dementia and their carers by:

- encouraging the development of Alzheimer associations
- promoting public awareness about dementia globally
- informing, educating and disseminating information to interested individuals and associations
- collaborating with other international organisations with similar interests
- encouraging research into the impact of dementia worldwide.

ADI's work focuses on stimulating and encouraging international exchange of information about dementia

care, raising awareness about the impact of dementia globally and developing effective Alzheimer associations. ADI's activities are outlined below.

Supporting Alzheimer associations

ADI believes that a strong, effective national Alzheimer association is better able to meet the needs of people with dementia and their carers. This belief led to the development of the Alzheimer University, a capacity-building programme designed for Alzheimer associations. The programme is a series of workshops and residential training courses to equip staff and volunteers of Alzheimer associations with the skills to develop their organisations. Topics have included leadership, strategic planning, communications, effective governance, and recruiting and supporting volunteers. A special Alzheimer University programme, 'Building an Alzheimer Association', is offered to new associations in developing countries. This year ADI launched the first Alzheimer University programme on advocacy and provided training on how to make dementia a healthcare priority with governments; it featured case studies from successful dementia advocacy campaigns. To date, over 60 countries have participated in the Alzheimer University.

ADI encourages partnerships between Alzheimer associations and has a twinning programme, where formal two-way collaborations to share information and skill between associations are established. ADI provides resources and support to enable twins to visit each other and develop a work plan; ADI then monitors progress.

Annual international conference

ADI's annual conference was the first international conference on dementia and is the longest running. Each year ADI's member groups and others come together to exchange information and to learn and share with one another. The ADI conference is unique in that it brings together a wide range of individuals and groups with an interest in dementia. Updates on research and the latest strategies for good dementia care are highlighted from around the world. A special feature of the conference is the involvement of people with dementia in plenary sessions and workshops speaking out about their experience of living with dementia. A different ADI member hosts the conference each year. The 2006 conference will be held in Berlin, Germany, on 12–14 October (see <http://www.alzheimer2006.de>) and will be marking the centenary of when Dr Alois Alzheimer first described the disease that would bear his name.

Raising awareness

Recognition of dementia as a disease and raising awareness are important priorities for each country. Dementia is surrounded by myth. For example, in

Nigeria a study of ten religious ministers in Anambra found that all ten believed that dementia was caused by evil spirits and the treatment used by the churches included fasting, prayers, beating, exorcism and dancing. The role of an Alzheimer association is critical in dispelling such myths. The provision of accurate and reliable information is a proven route to greater understanding and recognition.

World Alzheimer's Day, on 21 September each year, is ADI's annual awareness-raising campaign. ADI coordinates World Alzheimer's Day and produces and distributes publicity materials to its members and other interested parties. Last year 60 countries participated. This year the theme is 'No time to lose' and is a call for action for governments to prepare their health and social systems for the consequences of dementia and for individuals and organisations to work together to make dementia a global health priority.

ADI produces booklets, factsheets and videos on a variety of dementia-related topics in English and Spanish. ADI maintains a website and produces an international newsletter, *Global Perspective*. ADI members have access to an intranet site that provides information and resources from Alzheimer associations worldwide. ADI has a distinguished international medical and scientific advisory panel.

Supporting research

ADI's 10/66 Dementia Research Group trains researchers, particularly in low- and middle-income countries, on how to assess the impact of dementia nationally, and how to enable primary healthcare workers to diagnose and manage dementia. 10/66 gets its name from the fact that less than 10% of all population-based dementia research is directed towards the 66% or more of all people with dementia who live in low- and middle-income countries.

10/66 is supported by the World Health Organization and is a collaboration between ADI and the Institute of Psychiatry, London. Currently 10/66 is conducting population-based studies on prevalence and risk factors for dementia in China, Russia, Brazil, India, Cuba and Venezuela, and has recently been awarded a large grant from the Wellcome Trust to carry out incidence studies in these countries. When completed, this will be the largest international dementia data-set. 10/66 research results are disseminated at ADI conferences and symposia at other related international conferences and in research journals.

Conclusion

ADI has developed from its early beginnings in 1984 into a worldwide movement representing the voice of people with dementia and their families. ADI is committed to working with members to ensure that people with dementia and their families are able to access support and information to enable them to meet the demands of living with dementia.

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