

Ageways

Practical issues in ageing and development
Issue 78 / March 2012

Ageing and dementia

What is dementia?

The growing problem
of dementia

Ways to reduce the risk

Helping carers to care

Practical responses



**HelpAge
International**

age helps

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Future issues

Issue 79 (July 2012) HIV and AIDS

We welcome articles for consideration. Please send them three months before the month of publication.

Front cover

A woman in Brazil receives the care she needs. Photo: Armando Queiroz

This issue of Ageways was edited by Celia Till, HelpAge International and Sarah Smith, Alzheimer's Disease International

Comment

Collaborating for better care

Welcome to *Ageways* 78. Population ageing is a major achievement of better healthcare. But as a result, we are seeing many more people getting Alzheimer's disease and other dementias.

Policy-makers have been slow to see the implications of ageing for health systems, and most governments are not prepared for the dementia epidemic. However, there are some good signs. The UN's first-ever High-level Meeting on Non-communicable Diseases in September 2011 made a breakthrough by recognising the importance of ageing and Alzheimer's disease.

The World Health Organization will set out a plan of action on non-communicable diseases by the end of 2012. Collaboration between organisations working on older people's issues and dementia is needed to strengthen support for people affected by dementia and ensure concrete action on older people's health. HelpAge International and Alzheimer's Disease International will work together to influence this process.

Marc Wortmann, Executive Director, Alzheimer's Disease International and Sylvia Beales, Head of Strategic Alliances, HelpAge International

Campaigns

Age Demands Action

At least 62,000 older people and 171 organisations in 59 countries took part in the global Age Demands Action (ADA) movement in 2011.

They met 140 politicians, including 89 senior government ministers, and won policy pledges in 30 countries. In Sudan, for example, the Ministry of Social Welfare has agreed to provide health insurance cards for 4,000 older displaced people in west Darfur, and to give older people priority seating in buses across the country.

The Kenyan Minister for Justice has pledged better protection from violence for older people. In Indonesia, more older people will receive homecare through the government's expanded programme. In Pakistan, transport associations have pledged to halve fares for older people. In Moldova, the Minister of Labour has promised to add 10 per cent to the social pension.

In many countries, older people organised colourful street events and petitions to raise public support.



AGECO



COSE

Older people from Costa Rica (left) to the Philippines (above) took part in Age Demands Action.

This was the fifth year of ADA, the only globally coordinated campaign led by older people. Unprecedented media coverage led to an estimated 50 million people worldwide hearing about ADA.

Although ADA culminates in a day of action on 1 October, International Day of Older Persons, it includes activities throughout the year. In 2012, ADA campaigners will put more pressure on politicians to turn their policy pledges into action on key dates including 7 April, World Health Day (which is on the

theme of Ageing and Health) and 15 June, World Elder Abuse Day.

ADA leaders in Latin America also plan to attend the Intergovernmental Conference on Ageing in Latin America and the Caribbean in Costa Rica in May to campaign for a regional convention on older people's rights.

Find out more and sign the ADA petition: www.helpage.org/get-involved/campaigns

Do you want to take part in ADA in 2012? Email: campaigns@helpage.org

Letters

Gaps in healthcare

In 2011, HelpAge International worked with project partners and Alzheimer's Disease International (ADI) members and local Alzheimer associations in Bolivia, Colombia and Peru to assess people's access to dementia services.

Consultations with older people and families affected by dementia showed there was a massive gap between their needs and the support available from health services, local governments and the community.

Reviews of national mental health plans and older people's health plans, and interviews with health authorities, confirmed that mental health programmes are low priority. Health staff, especially at the community level, lack training and medicines for detecting, diagnosing and treating dementias.

Initiatives of Alzheimer groups and local NGOs are certainly helping, but they are not enough. HelpAge is planning to collaborate with ADI members to improve understanding of ageing and dementia, show what works and influence policy.

*Catherine Dusseau, Regional Health Adviser, HelpAge International Latin America Regional Development Centre (address on page 15).
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Dementia in rural Nigeria

Fantsuam Foundation is supporting a study of dementia in the Kafanchan area of Nigeria. We are using interviews, focus group discussions and participant observation to document attitudes, available support and coping strategies of carers and communities.

In rural Nigeria, there is stigma attached to taking older people with behavioural symptoms of dementia to hospital. Local understanding of dementia as an illness is not common. Behavioural symptoms are explained away as part of the ageing process, karma or witchcraft. Memory loss is usually attributed to ageing. The cost and inconvenience of seeking expert opinion and care makes informed care for people with dementia uncommon.

John Dada, Fantsuam Foundation, Kafanchan, Kaduna State, Nigeria (by email).

Francy, 73, from Colombia was diagnosed with Alzheimer's disease seven years ago. Her husband Francisco, 80, is her main carer. "We have access to basic consultation and hospital care but there is no specific care for older people with Alzheimer's and no advice on prevention either," he says.



María del Pilar Zubuaga

Stigma of mental illness

I recently read about something that happened in a posh locality of Delhi. Two sisters were living alone in their house. Their parents were both dead and their brother had left to live separately. They had dementia and confined themselves to their house. Their neighbours and brother eventually rescued them and took them to hospital. One sister was in a state of deep depression and expired.

Psychiatrists say that this case showed the lack of awareness in society and stigma attached to mental illness. I was

shocked to read about this incident at my present age of nearly 95 years.

Mahindar Singh, Indian Federation on Ageing, S-314, Panch Shila Park, New Delhi 110017, India.

We welcome letters

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Include your name, organisation (if any) and postal address. Letters may be edited.

New publications

HelpAge International has published the following guidelines:

Protecting older people in emergencies: good practice guide

This guide for humanitarian aid agencies draws on project experience to recommend how to protect older people's rights in emergencies and integrate their contributions into interventions. It covers shelter and latrines, livelihoods, food and registration, family and community structures, data, healthcare, and mainstreaming ageing.

www.helpage.org/resources/publications

Guidance on including older people in emergency shelter programmes

These guidelines recommending five key action points for including older people in emergency shelter programmes are now available in French, Russian and Spanish.

www.helpage.org/resources/publications

Practical guidelines series

This new section of HelpAge International's website contains practical guidelines for programme managers and people working with older people, drawing on experience in the HelpAge network.

www.helpage.org/resources/practical-guidelines



Obituary: Luz Barreto

We are very sorry that Luz Barreto, a member of HelpAge International's board of trustees, died in October 2011 after a short illness. As vice-president of the Working Group of NGOs for Older People, a HelpAge Affiliate based in Lima, Peru, Luz made a tremendous contribution to achieving positive social change for children and older people in Latin America. She will be greatly missed.

The growing problem of dementia

Jan Killeen explains why dementia is affecting more and more older people and calls for action to protect their rights.

“Dementia” is an umbrella term describing a group of diseases that gradually cause brain cells to die. Let’s start by getting rid of the myths about dementia:

- Dementia is not a normal part of ageing.
- It is not catching.
- It certainly does not mean that the person is wicked or possessed by spirits.

More than just memory loss

Dementia is a complex illness. Usually one of the first signs is forgetfulness. This is why dementia can be hard to detect at an early stage – because, as we age, we do become more forgetful.

Loss of short-term memory causes the person to feel insecure, agitated and sometimes withdrawn or angry when they are unable to make themselves understood. The disease goes on to damage parts of the brain that help us carry out everyday tasks, such as looking after our own health and hygiene. It affects our ability to think straight and to find the right words to express our thoughts, feelings, needs and wishes.

As the person’s mental ability declines, they may fail to recognise the faces of close family and friends. They may become lost in places they know well and lose all sense of time.

It is often hard for families to understand what is happening when the person’s behaviour changes, causing them major

stress. Understanding the illness and knowing how best to respond is vital to helping the person with dementia feel safe and secure.

More older people affected

Thanks to improvements in public health, our world is ageing, and this is to be welcomed. However, age is the greatest risk factor for dementia. Worldwide, about one person in nine over the age of 65 has Alzheimer’s disease. The proportion rises sharply with increasing years, reaching about one person in four over the age of 85.

Population ageing is leading to a steep rise in dementia cases, especially in low-income and middle-income countries. The World Alzheimer Report 2011, published by Alzheimer’s Disease International (ADI), estimated that by 2050, the number of people living with dementia would rise from 36 million to 115 million, and the proportion living in low-income and middle-income countries would rise from 58 per cent to 71 per cent.

Dementia is by far the greatest cause of dependency in older people and incurs an enormous cost. Worldwide, the cost of caring for people with dementia was estimated to be US\$604 billion in 2010, equivalent to more than 1 per cent of global GDP. Research shows that families meet half of these costs from their own income.

Alzheimer’s Disease International

Alzheimer’s Disease International (ADI) is the global umbrella organisation of more than 75 Alzheimer associations throughout the world. We work for an improved quality of life for people with dementia and their carers. We believe that addressing the social and economic impact of the disease must be a high priority for every nation, and that collaboration to find solutions is vital.

ADI supports the 10/66 Dementia Research Group which is currently conducting the largest-ever population-based research into dementia, non-communicable diseases and ageing in 20 low-income and middle-income countries (see page 13).



Abuse and discrimination

Because people with dementia lose their capacity to make decisions in their own interests, they find it harder to protect their rights and are therefore often at greater risk of abuse, including physical violence, mental abuse, neglect, maltreatment or financial exploitation. They become easily suggestible – for example, they may be easily persuaded to allow strangers into their homes and to give away their possessions.

People with dementia face discrimination in every aspect of their lives because of the social perceptions of ageing, combined with stigma attached to dementia. Stigma is a main barrier to obtaining care. It prevents people from talking about dementia, perpetuating the false belief that dementia is a normal part of ageing, and that nothing can be done about it. Families are often too embarrassed to ask for help.

Women are particularly badly affected because they live longer, so they are more likely to get dementia, they already face gender discrimination, and they are more likely to be poor.

Rarely diagnosed

Early diagnosis of dementia enables the person to take part in planning their future and deciding about care and



Katherine Leong, Malaysia

Human rights and dementia

A human rights approach to dementia care can improve policy and practice. Alzheimer Scotland has produced a Charter of Rights for People with Dementia and their Carers, which has been adopted by the Scottish Government (see page 13).

The Charter's principles underpin the National Dementia Strategy for Scotland which was launched in 2010. The Charter brings together key rights statements drawn from existing international conventions and treaties – and follows the rights that people with dementia have throughout their illness, from early diagnosis to end-of-life care.

An early diagnosis followed by good care can delay or reduce dementia symptoms.

treatment. There is evidence that if a person receives a diagnosis early on, followed by good health and social care, the symptoms of dementia can be delayed or reduced. This reduces the strain on their family and saves significant public and personal costs.

However, research shows that most people living with dementia have never received a formal diagnosis. Studies suggest that, worldwide, 28 million out of the 36 million people with dementia have not received a diagnosis, and therefore have no access to treatment, care or organised support. Even in high-income countries, only about 20-50 per cent of dementia cases are diagnosed.

Urgent need for action

Dementia is among the most significant social, health and economic crises of the 21st century. Yet older people with dementia are generally “invisible” in public health planning, and late diagnosis means they are unable to plead their own cause.

Access to healthcare is a fundamental human right – people with dementia are entitled to the highest standard of healthcare including timely diagnosis under the UN Convention on Human Rights for Persons with Disabilities.

National governments need urgently to develop strategies to improve access to healthcare for people with dementia and provide appropriate support:

- Public awareness campaigns and public information are needed to help people see that dementia is an illness and nothing to be ashamed of, and to encourage them to ask for help. Campaigns should also promote risk-reduction measures such as healthy diets and exercise.
- Individuals and their families need access to early diagnosis, treatment and support. This should include information, advice, and practical and emotional support throughout the illness, so that they can continue to care for the person and prevent them from developing other chronic diseases. People with dementia also need access to drug treatments that can delay or reduce symptoms.
- Healthcare professionals (community-based doctors and nurses) need training in how to detect dementia and how to provide treatment and support.
- The highest quality of care should be provided throughout the illness in the community and institutions.
- Laws are needed to protect the rights of people with dementia.

Collaboration between health and social care agencies is essential to provide better services. Collaboration between non-governmental organisations and relevant agencies at an international level is also vital to protect the rights of one of the most disempowered groups in society.

Progress is starting to be made at national and international levels in this rapidly-changing area of policy. The World Health Organization has made dementia a priority in its Mental Health Gap Action Programme, seeking to make treatment available in resource-poor countries. This is a timely and welcome move.

We also warmly welcome the outcome document of the UN High-level Meeting on Non-communicable Diseases in September 2011. As a result of lobbying by a coalition of agencies, including ADI and HelpAge International, this recognises dementia as a major public health issue and the need to invest in research.

ADI is now working with other agencies to release a new report later in 2012, which will focus on stigma, a huge barrier to reaching those most vulnerable.

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Combining expertise

Narendhar Ramasamy describes how two organisations in India are combining their expertise to improve the prospects of people with dementia.

HelpAge India is a leading provider of care homes for older people in India and supports hundreds of senior citizens' associations. Alzheimer's and Related Disorders Society of India (ARDSI) provides services to people with dementia and their families through its 16 chapters across the country.

In 2011, the two organisations came together to raise awareness of dementia in care homes and senior citizens' associations, and screen care home residents for dementia. As well as leading to better care for people with dementia, the project highlighted some of the difficulties of assessing and caring for people with memory problems.

Questions and answers

The aim of this collaborative project was to combine the core competencies of both organisations – HelpAge India's network of senior citizens' associations and care homes, with the technical expertise of ARDSI's staff and volunteers.

A team from ARDSI and HelpAge India visited 54 care homes and two senior citizens' associations in four cities – Delhi, Cochin, Bangalore and Kolkata. We gave presentations explaining what dementia is, how to reduce the risk of getting dementia, how to detect it and how to care for someone with dementia.

We then screened residents who said they had memory problems and had volunteered to be screened. We used the Mini Mental State Examination (MMSE), a set of about thirty questions which is widely used by doctors to test people's cognitive ability and screen them for dementia. Experts from ARDSI read out the questions and recorded residents' responses.

The results were analysed using computer software developed by HelpAge India. The software makes it easier not

only to analyse the initial results, but also to compare these with the results of follow-up screenings. This shows if a person's mental ability is deteriorating. Being able to see trends helps doctors to plan treatment programmes.

Our visits gave 2,358 people a better understanding of dementia. We screened 1,221 care home residents and identified 329 who had dementia symptoms. We recommended follow-up visits to local doctors, hospitals or mobile medical units, and arranged training for carers in homes and also for family carers.

Useful lessons

The project raised some important issues. It quickly became clear that most of our audiences knew very little about dementia, so we changed the way we started our presentation, asking if anyone had any problems with their memory and discussing the possible reasons.

We also found that the questionnaire had limitations. Some residents felt intimidated by it and were unwilling to talk about their symptoms. More commonly, they deviated from the questions and talked about other health problems, especially joint pains, ear, nose and throat infections, and problems with eyesight. They were more concerned about how to get and pay for treatment for these, than talking about dementia.

Some residents had other forms of cognitive impairment, such as depression, metabolic disturbances, chronic infections, and side-effects of medication. Because our project focused on dementia, we could not investigate these.

The project also raised issues for care homes. Staff were already very busy, making it difficult for them to provide any specialist care for people with dementia. With more staffing, much more could be done, such as arranging



A new daycare centre has now been opened by ARDSI and HelpAge India (described on page 12).

yoga and exercise classes, monthly visits by a doctor, counselling, and help with bathing.

Building awareness of dementia is a continuous process. We concluded that we should continue to run this project, developing it to cover a broader range of health issues.

Influencing policy

ARDSI and HelpAge India have also been working together to influence government policies affecting older people.

For example, as members of a sub-committee set up by the Ministry of Social Justice and Empowerment, we convinced the sub-committee to recommend a number of provisions in the government's 2012-2017 five-year plan. These include assisted-living homes for people with dementia, enhanced social security measures and training for health workers in care of older people.

Overall, we have found that combining the competencies of our two organisations has been very beneficial.

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Home alone: providing care in the community

Fiona Hon, Chua Hui Keng, Susan Teo and Wendy Khon describe how frail older people in Singapore are being supported to live in their own homes.

In Singapore, most elders with dementia are placed in residential care early on in the course of the disease. However, living in the community can be a viable option if a customised network of services is created, as the case of Mr LCK shows.

Mr LCK, 71, has epilepsy, glaucoma and dementia. A few months ago, he was admitted to hospital after a fall. When he was ready to go home, the hospital referred him for community case management.

Mr LCK lives in a rented one-bedroom public housing apartment with a distant cousin. Though married, he is estranged from his wife and children and receives no support from them. The Tsao Foundation, under its service arm, the Hua Mei Centre for Successful Ageing has, since 1996, run a care management service led by a nurse and social worker team to enable frail elders such as Mr LCK to live in the community.

A challenging start

To control his epilepsy, Mr LCK needs to take medication and attend check-ups. However, because of his dementia, he often forgets to take his pills or gets the dose wrong. He also has eye drops for glaucoma, but does not take them correctly. To make things worse, he has no idea when his medical appointments are due or how to reach the hospital.

So, top of the task list for the care managers was to get Mr LCK to take his medication correctly to stabilise his condition. The nurse care manager packed his medicine into daily pill boxes, explained the regime to him and tested him to make sure he understood. She also taught him how to take his eye drops.

The “hide and seek” days

The day after the care managers first met Mr LCK, he was admitted to hospital again after another fall. After he was discharged, the care managers continued



Pills are packed into daily doses.

Tsao Foundation

visiting him to make sure he took his medicine. They faced some challenges. First, Mr LCK seemed to have forgotten what his pills were for and had thrown them all away. The nurse care manager had to start all over again to train him how to take them.

More challenges unfolded in getting Mr LCK to attend his medical appointments. When his next appointment came up, the home help service tasked to take him to the hospital could not find him. Mr LCK had forgotten about the appointment and gone out to have coffee with his friends.

Seeing improvements

Those were frustrating days, but as collaboration with the various social service agencies improved, a discernible support network started to be formed and the tasks became easier. Now, when Mr LCK's appointments are coming up, the home help who delivers his meals reminds him, and the Lions Befrienders Senior Activity Centre keeps a look-out for him to prevent him from wandering too far.

The care managers have also helped Mr LCK in other ways. They arranged for the number of meals he receives from the meal delivery service, provided by Dorcas Home Care, to be increased from one to two meals. They have improved his financial situation by helping him to re-enrol for public financial assistance and by making sure his flatmate contributes to the rent and running costs. They are also working with the hospital social workers to apply for a waiver of his medical fees.

While the care managers will continue to support Mr LCK in the community for as long as possible, they will also start to consider long-term care arrangements as his dementia progresses.

Fiona Hon and Susan Teo are care managers who are registered nurses, Chua Hui Keng is also a care manager who is the social worker and Wendy Khon is the care manager assistant who supports the team.

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What is dementia?

This article explains what dementia is, why it is important to diagnose it and how dementia is diagnosed.

The word “dementia” describes a number of progressive brain diseases that affect a person’s memory, thinking, behaviour and emotions. All types of dementia result in a decline in mental function, especially memory, which interferes with daily activities and social relationships.

Most types of dementia affect people later in life, generally over the age of 65. Most types affect men and women equally.

Dementia usually progresses steadily over a number of years. The speed at which it progresses varies from person to person. There is currently no known cure for most forms of dementia, although research in this area is continuing.

Dementia not only affects the person who has it, but can also be devastating for their family and carers.

What are the most common types of dementia?

There are many different types of dementia. The most common are:

Alzheimer’s disease

This accounts for 50-60 per cent of all cases. Alzheimer’s disease is caused by widespread damage to brain cells as a result of the development of protein “plaques” and “tangles”. Alzheimer’s produces slow decline of memory, language and thinking. The cause of the development of the protein build-up in the brain is not yet known, but it is likely that a number of factors, such as an unhealthy lifestyle and age (being over 65) are risk factors.

Vascular dementia

This is the second most common form of dementia, accounting for around 20 per cent of cases. It is caused by poor blood supply to the brain, which results in a series of mini-strokes. It produces a steady decline of memory and can cause periods of severe confusion or problems with thinking, concentration and communication.

Dementia with Lewy bodies

This is caused by abnormal collections of protein, known as Lewy bodies, appearing in the brain. Like Alzheimer’s disease, it is the result of the degeneration and death of nerve cells in the brain. It causes fluctuating memory problems, distressing hallucinations, stiffness, tremor (known as parkinsonism) and falls.

Fronto-temporal dementia, including Pick’s disease

This is a relatively rare cause of dementia which typically develops at an earlier age than Alzheimer’s disease. Fronto-temporal dementia is brought on by damage to the front of brain. In around one third to one half of all cases there is a family history of fronto-temporal dementia. As yet, the causes of non-inherited fronto-temporal dementia are not known. It results in gradual memory loss, early deterioration of social behaviour and early loss of language skills.



“I had time to plan ahead”

When I received the confirmation that I had Alzheimer’s disease, I was devastated, although I had suspected it for a while. I am a member of my local Alzheimer’s support group. From my research and personal experience I have found a method to counter the disease and lead a reasonably normal life.

I went through a denial phase at first and then I decided to read up more about this. The more I read, the more I, at first, despaired. Then I decided to fight the disease and try to stay healthy until a drug is found to delay its progress.

I think that I am one of the lucky ones who were diagnosed at a relatively early stage of the sickness. Thus I could plan the road ahead because I could still think coherently.

Early diagnosis enables the Alzheimer’s patient to delay the sickness for a number of years. This happened to me and can happen with many thousands (even millions).

John du Preez, 75, from South Africa was diagnosed with dementia four years ago. This is a shortened version of his testimony which appears with other testimonies by people with dementia in the World Alzheimer Report 2011 (details on page 13).

“I tap my head to find the words”

I have friends. That is why I can write more. It is still hot but there is a hint of autumn in the air. It has been extremely hot this summer and I have suffered from it. The word “September” and my feeling about September do not seem to be exactly the same.

I would have been happier if I could write fluently. What I write shows what I am. I write so carefully but there are many misspelled words. So I rewrite dozens of times. Why don't the words come? I tap on my head to pull out suitable words. Surprisingly, tapping is effective. Tapping softly, gently.

Autumn breeze will ask me: “How is it going?” Fully appreciating the words, I can feel I am not alone and keep my chin up. I have friends. That is why I can write more. I say to myself “lighten up”.

Osamu Mizuki, 73, from Japan was diagnosed with Alzheimer's disease five years ago.

Is dementia hereditary?

If a person's parent developed dementia in old age, then that person's chance of developing dementia in old age is slightly greater than for a person with no dementia in the family. There are a few, very rare cases where Alzheimer's disease does run in families. In these cases, there is a direct link between an inherited mutation in one gene and the onset of the disease. These tend to be cases of “early onset” Alzheimer's disease affecting people under the age of 60, or fronto-temporal dementia.

Can dementia be cured?

There is currently no cure for Alzheimer's disease or most other forms of dementia. However, acetylcholinesterase inhibitor drugs have been developed to slow down the progression of some types of dementia and alleviate symptoms. There is also much that can be done to help people with dementia manage symptoms such as memory loss, depression, anxiety and agitation.

Why is diagnosis important?

It is helpful to get a diagnosis of dementia as early as possible because:

For the person with dementia, a diagnosis provides an explanation for their symptoms and odd behaviour.

It gives them information about the cause of the disease and outlook. It initiates their access to resources and treatments and provides an opportunity to discuss the problem.

For the person's carer and family, a diagnosis should provide greater understanding of the person's symptoms and behaviour, as well as information to help them plan for the future. It also recognises the carer's role and gives them access to resources and support.

For health professionals and service providers, a diagnosis enables them to provide a more effective service. It also makes it easier for people with dementia and their carers to develop a trusting relationship with professionals.

For policy makers, an effective system for diagnosing people with dementia allows them to see the true scale of the problem. This will encourage them to support the development of appropriate services and training of professionals and volunteers.

How is dementia diagnosed?

The first step to diagnosis is usually when the person with dementia or someone in their family realises that something is wrong. The most common signs of dementia are memory loss, confusion and odd behaviour.

Family and friends are more likely to think that a person may have dementia if they are aware that memory does not normally decline significantly with age, and that poor memory should be investigated at any age.

The next step is to get a medical opinion. There is no single test for dementia. The doctor will make a diagnosis from the account given by the person's family and by talking with, observing and assessing the person who may have dementia.

Doctors follow four steps to make a diagnosis:

- 1. Listening** The first and most important step is to hear from the person and their family how the symptoms have developed.
- 2. Recognising symptoms** The doctor can only recognise the characteristic symptoms of dementia, such as memory loss, confusion and changes in personality, by asking the right questions and getting the person to carry out simple mental tests. Many doctors use a standard set of questions known as the Mini Mental State Examination.
- 3. Making the diagnosis** The doctor will use the information they have received and the results of the mental tests to work out whether the person has dementia, or whether their symptoms are caused by something else. If the person has dementia, the doctor will consider all of the symptoms the person is experiencing in order to determine what type of dementia it is.
- 4. Communicating the diagnosis** The doctor needs to discuss with the person and their family what seems to be the most likely cause of the symptoms, what sort of help is likely to be appropriate and how this can be obtained. If the diagnosis is dementia, the doctor should give the person some idea of the type and cause of their dementia.

With thanks to Alzheimer's Disease International (address on page 13).

Ways to reduce the risk

There is no guaranteed way to prevent dementia, but there are ways to reduce the risk, writes Marc Wortmann.

Can we prevent Alzheimer's disease and other forms of dementia? This is the subject of huge debate in the scientific world. The reason for the debate is that scientists prefer to find evidence from randomised controlled studies – the “gold standard” for testing new drugs – but these are not well suited to measuring dementia risk reduction strategies.

In randomised controlled studies, two groups of patients are each given a drug or a placebo (sugar pill) without knowing which they have received, and the results are compared after 12-18 months. However, prevention takes much longer than this – for some risk factors, 10 or 20 years. You cannot ask two groups of people to live what may be an unhealthy life for such a long time, just for research purposes, as it would be unethical.

Three long-term controlled studies that avoid these ethical concerns are currently being carried out in Finland, the Netherlands and France, as part of the European Dementia Prevention Initiative, launched in 2011.¹ These will assess the effectiveness of dementia risk-reduction strategies in more than 6,000 older people.

Meanwhile, scientific evidence on reducing the risk of dementia has to come from other research, mainly large, long-lasting population-based studies, in which several factors are tested and data is collected over a long period. Many such studies have been carried out. They were recently reviewed by researchers who tried to bring all the findings together.²



Leonardo Ramirez, Venezuela

Evidence suggests living a healthy life reduces the risk of dementia.

Key risk factors

Key modifiable risk factors (risk factors that can be changed, unlike age) seem to be:

- low education
- smoking
- low level of physical activity
- risk factors related to diabetes and vascular disease (disease of the heart and blood vessels), such as high blood pressure and obesity in midlife.

So we cannot say that it is possible to prevent dementia in an individual person. But on a population level, it seems to be clear that the risk can be reduced by:

- giving people better education (which stimulates the brain)
- promoting physical activity throughout life
- keeping an eye on blood pressure and cholesterol, especially in midlife (in people's fifties)
- stopping smoking.

In general, to live a healthy life is good for the body and the brain. It reduces your risk of many diseases which Alzheimer's disease and other forms of dementia are closely related to, especially heart disease and diabetes. Still, we cannot guarantee that a healthy life will prevent dementia – it only reduces the risk.

Policy recommendations

Policy recommendations are now being developed for all major chronic diseases, following the United Nations High-level Meeting on Non-communicable Diseases (NCDs) in September 2011.

These are likely to include measures to reduce smoking (such as banning advertising of tobacco products and increasing taxation), reduce salt consumption to lower blood pressure, reduce alcohol consumption, and promote combination drug therapy for those at high risk of heart disease.

The World Health Organization will propose global policy targets at its annual meeting in May 2012. Individual countries are supposed to use these to develop national targets.

Educating the public

Knowledge about risk factors has encouraged some organisations to run public awareness campaigns. In 2005, Alzheimer's Australia launched its Mind Your Mind campaign. The campaign aims to make people aware of the importance of brain health through community education sessions, training, media coverage, a mobile phone application and a website.

Based on epidemiological evidence, the campaign points the way to a healthy brain and reduced risk of dementia, addressing physical, mental and social activity, cardiovascular risk factors, diet, smoking, alcohol, and preventing head injuries. You can find out more at: <http://mindyourmind.org.au>

**Marc Wortmann is Executive Director, Alzheimer's Disease International (address on page 13).
Email: mwortmann@alz.co.uk**

1. European Dementia Prevention Initiative, www.edpi.org
2. Barnes D and Yaffe K, 'The projected effect of risk factor reduction on Alzheimer's disease prevalence', *The Lancet Neurology online*, September 2011, www.thelancet.com/neurology

Helping carers to care

People caring for someone with dementia need support themselves, writes *Sarah Smith*.

The experience of caring for a person with dementia can be very emotional. Family carers may find themselves feeling depressed, angry or alone, particularly as the disease progresses.

Carers require practical and emotional support to enable them to care effectively throughout the course of the disease and to look after their own health and wellbeing.

There is a distinct lack of support services at every level. In many countries, national Alzheimer associations and other patient groups provide advice and support to fill this gap. However, they often lack the capacity to extend this support countrywide or to reach more remote communities.

“I give her my love”

When we received the terrible news that my mother had Alzheimer’s nine years ago, I felt that the world had collapsed.

It is impossible not to feel sorrow, seeing her going away little by little. All I can do is give her my love, understanding and support. I demonstrate this at every bathtime, meal, change of clothes and when going for a walk, and in each hug, smile and kiss that I give her.

It is very sad, when this disease is advancing, to be left alone. Many friends and relatives do not know how to handle it and choose to go away. I must divide myself between being a caregiver-daughter, mother and worker. I give thanks to Casa Sol (Sun House), a daycare centre that helps us three days a week, and the Alzheimer Association of Costa Rica for their invaluable support.

My mother will never stop being my best friend. Although she doesn’t remember me, I know who she is and I will love her forever.

María Soledad Chaves Ortiz, carer and Secretary of the Alzheimer Association of Costa Rica (pictured with her mother)

What support is needed?

Carers generally require three types of assistance: information, practical help and personal support.

Information

Carers need information on all aspects of dementia and they need to know where to find help. The information they require will change as the disease progresses.

Practical help

Carers often need assistance with housework, shopping and preparing meals. These tasks can pose a particular challenge to members of the household who have not been responsible for them before.

Carers may also need help with installing safety aids and equipment or home security systems that will make their home a safer place for the person with dementia to live in.

In addition, carers may need help to care physically for the person with dementia, including assistance with bathing, getting up in the morning, dressing and going to bed at night.

Personal support

Personal support can make a real difference to the wellbeing of a carer and, as a result, to the standard of care that they can provide.

An example of personal support is respite services. Offering a carer the opportunity to have some time to

socialise, pursue their own interests or just spend time relaxing can have a very positive effect on both the carer and the person with dementia.

Respite may include taking the person with dementia away from their home for a short period – for example, to a daycare centre, or arranging for someone to come and care for the person at home.

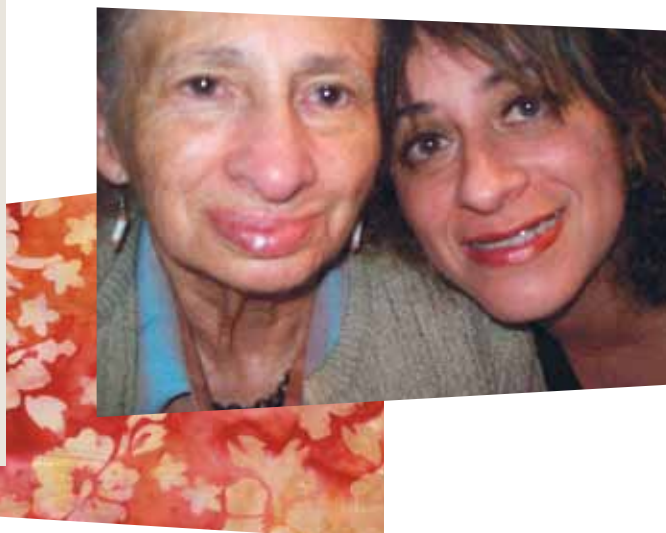
Support groups are also helpful, enabling carers to share their thoughts and feelings about caring with those in a similar situation. Many carers who have attended support groups say they have found them to be very beneficial.

Solving the problem together

Collaboration between like-minded organisations or individuals can play a significant part in providing high-quality support services for carers. The combination of knowledge, experience and resources not only extends the reach of the services available, but also enhances the reputation of each organisation involved.

Developing support services for carers can be a valuable start to a fruitful partnership. To find out whether there is a HelpAge network affiliate or Alzheimer’s Disease International representative in your country that you could work with, turn to page 14.

Sarah Smith is Communications and Administration Officer, Alzheimer’s Disease International (address on page 13). Email: s.smith@alz.co.uk



Useful book

Understanding Alzheimer’s Disease & Other Dementias by Dr Nori Graham and Dr James Warner describes how dementia is diagnosed and treated, and provides practical advice to help cope with the day-to-day problems (details on page 13).

Inspiring ideas

Around the world, there are many inspiring examples of practical activities that are helping people with dementia and their carers. Here are just a few.



TADA Chinese Taipei



Janet Wood, Zimbabwe



Alzheimer's Australia

Activities to stimulate the mind: group games in Taiwan (above), an art class in Zimbabwe (above right) and a "water wall" in Australia (below right).

Alzheimer café

The first Alzheimer café in the Netherlands was set up in 1997 by a clinical psychologist and the local Alzheimer association. People with dementia and their carers go to the café to share their experiences and get information about dementia. Similar cafés have since opened in other countries.

Daycare centre

The Delhi Chapter of Alzheimer's and Related Disorders Society of India (ARDSI) and HelpAge India have teamed up to open a dementia daycare centre in Delhi. ARDSI provides technical expertise and HelpAge India has sponsored the unit. The centre can accommodate up to 10 people. A van picks them up from home and drops them back in the evening. The centre is staffed by trained carers, nursing assistants, ARDSI volunteers and visiting doctors including a psychiatrist. The daily routines starts with a prayer, followed by yoga, games, television, lunch, a rest and evening refreshments.

Memory tour

In 2008, Muistiliitto ry, the national Alzheimer association in Finland, formed a partnership with the Ateneum Art Museum of the Finnish National Art Gallery to create a special Memory Tour for people with dementia. The tour included 11 works of art to look at, as well as items to smell and touch. Muistiliitto ry provided training to gallery staff in communicating with people with dementia, and information to nurses on how to use art with their patients.

School of Wisdom

The School of Wisdom was developed in 2004 by TADA Chinese Taipei in Taiwan as a therapeutic group activity. It encourages people in the early stages of dementia to exercise their bodies and minds, and helps carers by providing them with respite. The school offers classes in creative arts, music and physical exercise, such as the Brain Exercise Class and the Tradition-Passing Class.

Weekly art group

Zimbabwe Alzheimer's and Related Disorders Association (ZARDA) runs an art group for people with dementia. The group meets every Sunday at a country house where members can enjoy the landscape, be creative and keep their minds active. They are encouraged to walk through the grounds to get inspiration for their paintings.

Water feature

The Western Australia branch of Alzheimer's Australia has added a "water wall" to the garden at a daycare centre for people with dementia. The wall was made by centre members, staff and volunteers from terracotta and blue tiles. It adds to a variety of sensory experiences in the garden including highly-scented plants and colourful flowers.

For more information about these activities please contact Alzheimer's Disease International (address on page 13).

Resources

Organisations

Alzheimer's Disease International (ADI)

ADI is the umbrella organisation of Alzheimer associations around the world. ADI aims to help establish and strengthen Alzheimer associations, and to raise global awareness about Alzheimer's disease and all other causes of dementia.

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www.alz.co.uk

Alzheimer's Association

The Alzheimer's Association in the USA is the leading global voluntary health organisation in Alzheimer's care and support, and the largest private, non-profit funder of Alzheimer's research.

www.alz.org

Alzheimer's Australia

Alzheimer's Australia manages innovative national dementia programmes and services, supports research and carries out advocacy. Its Mind Your Mind campaign raises public awareness.

www.fightdementia.org.au

Alzheimer's Society

Alzheimer's Society works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland. It produces factsheets and other resources on a wide range of dementia-related topics, which are available on its website.

www.alzheimers.org.uk

10/66 Dementia Research Group

This is a collective of researchers carrying out population-based research into dementia, non-communicable diseases and ageing in low-income and middle-income countries.

www.alz.co.uk/1066

Scottish Dementia Working Group

The Scottish Dementia Working Group is a national campaigning group, run by people with dementia in Scotland.

www.sdwg.org.uk

Events

World Alzheimer's Day

World Alzheimer's Day takes place on 21 September each year to unite opinion leaders, people with dementia, their carers and families, medical professionals, researchers and the media from around the world.

www.alz.co.uk/world-alzheimers-day

Annual International Conference of Alzheimer's Disease International

ADI's annual conference provides a great opportunity to learn about achievements in the medical field, new research and best practices in dementia care, and to challenge perceptions of dementia.

www.alz.co.uk/ADI-conference

Publications

Understanding Alzheimer's Disease and Other Dementias

A resource for anyone who has, or may be worried that they, a family member or friend has dementia.

Dr Nori Graham and Dr James Warner, The British Medical Association Family Doctor Publications, 2009.

Price: £4.95 plus postage

<http://familydoctor.co.uk/node/29>

World Alzheimer Report

Report published each year by ADI, highlighting current research on topics including the numbers of people with dementia worldwide, the global costs and the benefits of early intervention and diagnosis. The 2012 report, due in September, will focus on stigma.

www.alz.co.uk/research/world-report

Websites

Alzheimer associations

Alzheimer associations provide information and support. They can advise you of services available in your area, and answer your questions.

www.alz.co.uk/associations

Information in other languages

This page provides links to general information about dementia in 49 different languages.

www.alz.co.uk/other-languages

I CAN! I WILL! idea library

This is a library of ideas to help people around the world stand up and speak out about Alzheimer's disease and related disorders.

www.alz.co.uk/icaniwill

Non-communicable diseases

This section of HelpAge International's website contains updates and facts on non-communicable diseases including dementia.

www.helpage.org/what-we-do/health/non-communicable-diseases

International agreements and programmes

Convention on the Rights of Persons with Disabilities (2006)

This attempts to change the perception of disability and encourages societies to recognise that all people must be given the opportunity to live their life to the full.

www.un.org/disabilities/convention/conventionfull.shtml

Mental Health Gap Action Programme

The World Health Organization Mental Health Gap Action Programme (mhGAP) aims to scale up services for mental, neurological and substance use disorders, especially in low-income and middle-income countries.

www.who.int/mental_health/mhgap

Political declaration of the UN High-level Meeting on Non-communicable Diseases, September 2011

This recognises the importance of mental and neurological disorders, including Alzheimer's, and the need to provide equitable access to effective programmes and healthcare interventions for these.

http://ncdalliance.org/sites/default/files/rfiles/UN%20Resolution%20A64-52_0.pdf

Charter of Rights for People with Dementia and their Carers in Scotland

The Charter reflects the standards set by the United Nations and other international instruments.

www.dementiarights.org/charter-of-rights

Get connected!

Collaboration between different organisations working on ageing and dementia helps to improve services and creates a stronger base for lobbying.

The HelpAge global network has 94 Affiliates in 62 countries with expertise in older people's issues (listed on the opposite page).

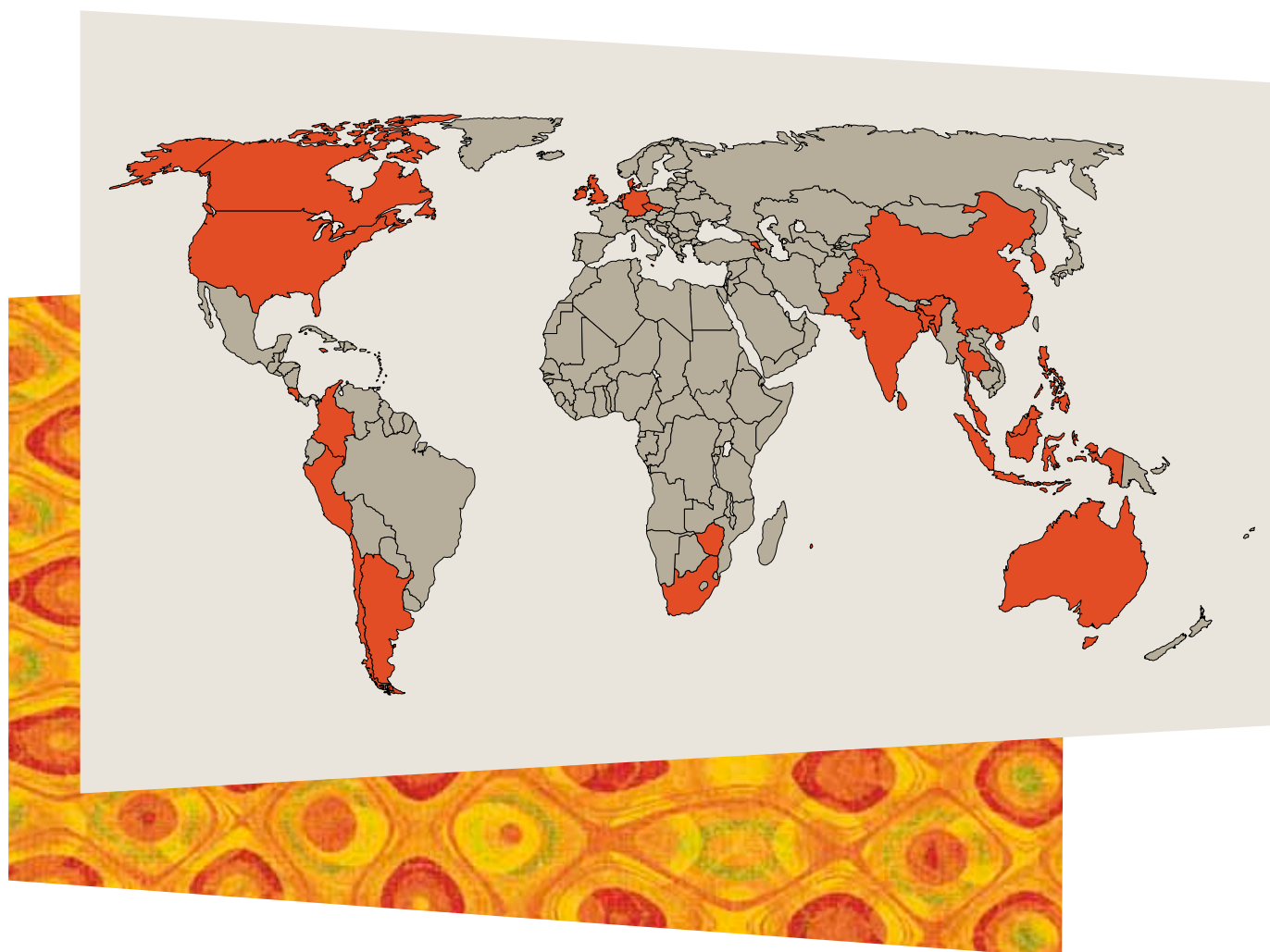
Alzheimer's Disease International (ADI) has national member associations in 76 countries that provide a range of services and information for people with dementia and their carers.

This map shows the 32 countries in which there is both a HelpAge Affiliate and a national Alzheimer association.

If you are in one of these countries, you could get in touch with a HelpAge Affiliate or Alzheimer association and see how you can work together. You can obtain contact details from ADI (see page 13) or your nearest HelpAge regional centre (see page 15).

Countries with Alzheimer associations and HelpAge Affiliates

Argentina, Armenia, Australia, Bangladesh, Barbados, Canada, Chile, PR China, Colombia, Costa Rica, Czech Republic, Denmark, Germany, India, Indonesia, Ireland, Jamaica, Malaysia, Malta, Mauritius, Netherlands, Pakistan, Peru, Philippines, Singapore, South Africa, South Korea, Sri Lanka, Thailand, UK, USA and Zimbabwe.



Affiliates

More than 90 organisations in over 60 countries are affiliated to HelpAge International, forming a global network standing up for the rights of older people.

Caribbean

Action Ageing Jamaica
Dominica Council on Ageing
Extended Care through Hope and Optimism (ECHO), Grenada
HelpAge Barbados
HelpAge Belize*
HelpAge St Lucia
Old People's Welfare Association (OPWA), Montserrat
REACH Dominica
Society of St Vincent de Paul, Antigua
St Catherine Community Development Agency (SACDA), Jamaica

Eastern, West and Central Africa

Current Evangelism Ministries, Sierra Leone
Ethiopia Elderly and Pensioners National Association (EEPNA), Ethiopia
HelpAge Ghana
HelpAge Kenya*
Kenya Society for People with AIDS (KESPA)
Mauritius Family Planning Association RECEWAPEC, Cameroon
Rift Valley Children and Women Development Organisation (RCWDO), Ethiopia
SAWAKA, Tanzania
Senior Citizens' Council, Mauritius
Sierra Leone Society for the Welfare of the Aged
South Sudan Older People's Organisation (SSOPO)
Sudanese Society for the Care of Older People (SSCOP)
Tanzania Mission to the Poor and Disabled (PADI)
Uganda Reach the Aged Association (URAA)

Southern Africa

Age-in-Action, South Africa
APOSEMO, Mozambique
Elim Hlanganani Society for the Care of the Aged, South Africa
HelpAge Zimbabwe
Maseru Senior Women's Association, Lesotho

Muthande Society for the Aged (MUSA), South Africa
Senior Citizens' Association of Zambia
VUKOXA, Mozambique

East Asia and Pacific

CASCD (formerly RECAS), Vietnam
China National Committee on Aging (CNCA)
Coalition of Services of the Elderly (COSE), Philippines
Council on the Ageing (COTA), Australia
Fiji Council of Social Services (FCOSS)
Foundation for Older Persons Development (FOPDEV), Thailand
HelpAge Korea*
Helping Hand Hong Kong
Instituto de Acção Social, Macau
Mongolian Association of Elderly People
National Council of Senior Citizens Organisations Malaysia (NACSCOM)
Office of Seniors' Interests, Australia
Senior Citizens' Association of Thailand
Senior Citizens' Council of Thailand
Singapore Action Group of Elders (SAGE)
Society for WINGS, Singapore
Tsao Foundation, Singapore
USIAMAS, Malaysia
Vietnam Association of the Elderly (VAE)
Yayasan Emong Lansia (YEL), Indonesia

South Asia

Bangladesh Women's Health Coalition (BWHC)
Gramin Vikas Vigyan Samiti (GRAVIS), India
HelpAge India
HelpAge Sri Lanka*
Pakistan Medico International
Resource Integration Centre (RIC), Bangladesh

Eastern Europe and Central Asia

Dobroe Delo, Russia
Lastavica, Serbia
Mission Armenia
Second Breath (Gerontological Association of Moldova)
Resource Centre for Elderly People (RCE), Kyrgyzstan

Western Europe

Age Action Ireland
Age UK
Caritas Malta HelpAge
Centre for Policy on Ageing, UK
Cordaid, Netherlands
DaneAge Association
HelpAge Deutschland*
Slovene Philanthropy
WorldGranny, Netherlands*
Zivot 90, Czech Republic

Latin America

AGECO, Costa Rica
CAPIS, Peru
Caritas Chile
Centro Proceso Social, Peru
CESTRA, Colombia
CooperAcción, Peru
Fundación Horizontes, Bolivia
Haitian Society for the Blind (SHAA)
IPEMIN, Peru
ISALUD, Argentina
Peru Coordinating Group for Older People (Mesa de Trabajo)
Pro Vida Bolivia
Pro Vida Colombia
Pro Vida Perú
Red de Programas para el Adulto Mayor, Chile

North America

AARP
HelpAge Canada*
HelpAge USA*
West Virginia University Center on Aging, USA

Middle East

El-Wedad Society for Community Rehabilitation (WSCR), OPT

*HelpAge sister Affiliates



HelpAge regional centres

Caribbean

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Job title	Organisation	
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City		
Postcode/zip code	Country	
Tel		
Email (include if possible)		

Who do you work for?

- Older people's organisation/pensioners' association
- Community-based/non-governmental organisation
- Local government
- National government
- Health service/social care
- Research institute/university
- Other (please specify)

What is your job?

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- Health worker
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Friends and memories

In Argentina, memory stimulation workshops are helping people with dementia to use their minds and make new friends.

The Argentinian Alzheimer association, ALMA, provides services to people with dementia and their families across the country. ALMA organises volunteer-based help with daily activities, talks by health professionals and lawyers, and support groups for family members.

In Buenos Aires, ALMA runs weekly memory stimulation workshops for people with mild to moderate dementia for seven months of the year. There are two separate sessions for people with mild and moderate dementia, each attended by about twenty people, most of them women. The sessions, which last for three hours, are led by a psychologist with the help of four volunteers.

A variety of activities are organised to help people exercise their minds in a relaxed and friendly way. For example, newspaper cuttings, photos and films of past events are used to trigger people's memories and encourage them to talk about their own experiences. People are also reminded about what is happening in the present, and are given games, tasks and puzzles to do to encourage them to use skills such as concentration and deduction.



Music and dancing are popular activities.

ALMA

“There is real companionship and friendship. There is also humanity and a sense of community.”

Social activities such as singing, games and discussions are particularly successful. Music is an important part of the workshops, with a music therapist coming in to provide support. The emphasis is always on encouraging people to use the abilities they still have, and to link activities to their personal history, such as the work they used to do, places they have been to and their interests and hobbies.

The workshops clearly make a big difference to the lives of those who attend them. “I’m very happy to be part of the group,” says one man called Marino. “I long for Thursdays and the day flies by.”

Another participant, Aurora, speaks for many when she talks of the companionship she enjoys. “I’m really fond of my friends here. There is real companionship and friendship. There is also humanity and a sense of community.”

With thanks to **Asociación Lucha contra el Mal de Alzheimer y alteraciones semejantes (ALMA)**, Lacarra 78, Buenos Aires, Argentina
Email: info@alma-alzheimer.org.ar
www.alma-alzheimer.org.ar

HelpAge International helps older people claim their rights, challenge discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives.

Copies of *Ageways* are available free of charge to people working with older people. Please use the order form on page 15 or at: www.helpage.org/ageways
You can also download *Ageways* as a PDF from this address.

Ageways exchanges practical information on ageing and development, particularly good practice developed in the HelpAge network. It is published twice a year.

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