



Global Perspective

A newsletter for Alzheimer's Disease International, The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.

Old age or disease? Recognising dementia

This year's World Alzheimer's Day™ campaign, 21 September, focuses on the importance of recognising the early symptoms of dementia. The underlying message is that dementia and memory problems are not a normal part of ageing.

Many people still think of dementia and becoming more forgetful as a normal consequence of getting older. A recent survey commissioned by Alzheimer Scotland – Action on Dementia showed that 31% of people asked believe that dementia is a normal part of ageing. Worryingly, it is those over 65 who are most likely to hold this opinion. This misconception amongst older people is concerning as it is this group who are most at risk of developing dementia and in need of information about the help that is available.

Professor John Bayley, husband of Dame Iris Murdoch (the UK novelist about whom the film *Iris* was made), describes in this year's World Alzheimer's Day™ campaign what it was that made him go to the doctor with Iris. Professor

Bayley said, 'I first noticed Iris was not herself in a public place. Our lives at home went snugly on just as usual – but when talking at a meeting, Iris suddenly made no sense and seemed bewildered. The audience was upset and embarrassed.' He then described how, after seeing a specialist, 'Iris's brain scan revealed the unmistakable Alzheimer symptoms'.

Memory loss is usually the first sign that something is not quite right. However, there are other common symptoms of dementia – including difficulty performing familiar tasks, problems in naming everyday objects, getting lost easily (even in familiar places) and changes in mood, personality and behaviour.

Recognising the symptoms of dementia is the first step towards receiving a diagnosis and help. Although there is no cure for most causes of dementia, a diagnosis can help reduce the anxiety of a



Dame Iris Murdoch with her husband Professor John Bayley

person with dementia and their family, as well as providing a chance to benefit from existing treatments, access to resources and information, and more time to plan for the future.

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Alzheimer associations, along with other organisations and individuals, will be marking World Alzheimer's Day™ all around the world with various events – including Memory

Walks, leafleting campaigns and seminars. For more information about World Alzheimer's Day™ and to find out what you can do, visit ADI's updated website www.alz.co.uk



Alzheimer's Disease International

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Send us your comments

If you have any comments about our items for the newsletter please contact the Secretariat. Articles and letters for the next issue of Global Perspective to arrive by 1 October 2002.

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ANNOUNCEMENTS AND CONFERENCES

2002

4-7 September
4th International Congress of Neuropsychiatry
Buenos Aires, Argentina
Email: info@neuropsychiatry.org.ar
Web: www.neuropsychiatry.org.ar

5-8 September
ADI's 5th Asian Pacific Regional Meeting
Kowloon, Hong Kong
Fax: +852 2338 0772
Email: gemma@hkuspace.hku.hk
Web: www.hkada.org.hk

12-14 September
3rd Deutschen Alzheimer Gesellschaft Kongress
Acting Together
Friedrichshafen, Germany
Tel: + 30 31505733
Fax: + 30 31505735
Email: deutsche.alzheimer.ges@t-online.de
Web: www.ctw-congress.de/alzheimer

3-5 October
2nd International Symposium on Alzheimer's Disease in the Middle East
Antalya, Turkey
Tel: +1 773 784 8134
Fax: +1 208 575 5453
Email: meetings@worldeventsforum.com
Web: www.worldeventsforum.com/alz.htm

4-6 October
ARDSI's VIII National Conference
Goa, India
Tel: +00 91 (0)832 414027/293315
Email: apdias@goatelecom.com

23-26 October
IPA's Asia Pacific Regional Meeting
Dementia, Depression, and Suicide in the Elderly: Cultural and Clinical Aspects

Hong Kong
Tel: +1 847 784 1705
Fax: +1 847 784 1701
Email: ipa@ipa-online.org
Web: www.ipa-online.org

2003

18-21 March
Alzheimer's Australia National Conference and ADI's 6th Asia Pacific Regional Meeting
Melbourne, Australia
Tel: +61 3 9645 6311
Fax: +61 3 9645 6322
Email: info@wsm.com.au
Web: www.alzvic.asn.au

30 April-3 May
III Pan American Congress of Gerontology
Buenos Aires, Argentina
Tel/fax: +54 11 4961 0070
Email: sagg@connmed.com.ar
Web: www.sagg.org.ar

23-26 October 2002
18th Alzheimer's Disease International Conference
Dementia: meeting the challenge together
Barcelona, Spain
Tel: +34 93 201 7571 Fax: +34 93 201 9789
Email: suport@suportserveis.com
Web: www.alzheimer2002.com

Visit <http://www.alz.co.uk/help/events> for more conference announcements

Updates in dementia research

Research in various aspects of dementia, and particularly Alzheimer's disease, has exploded in recent years. In the USA, for example, there are currently at least 17 new drugs in various stages of trial for the treatment of Alzheimer's disease.

Broadly speaking, research in dementia falls into four categories:

- Epidemiology
- Pathology and genetics
- Management and treatment
- Ethical issues

It's worth understanding what each of these is and how they are relevant to you.

Epidemiological studies

Epidemiological studies look at the question of how many people in a community develop dementia. This information is particularly relevant to organisations planning for the current and future needs of people with dementia. Such studies also aim to identify the risk factors which increase an individual's risk of developing a dementia. This issue of identifying risk factors is central to public policy and personal decisions aimed at prevention.

Genetic studies

Genetic studies aim, as an end point, to provide clinicians with the



Carer story from Greece by Anastasia Filipopoulou

Living with Stathis

Two painful eyes staring at me was what remained of a man who had been full of life. This man was Stathis, my husband.

His spirit and athletic physique is the portrait of my Stathis. The love and care that I received over the last 32 years of my life, were the most precious gift offered to me from Stathis, my husband.

Suddenly our beautiful world changed. Sports, reading, dancing, sex and entertainment vanished. Stathis had no interest at all in anything. I became worried because I had a totally different person now in my life. I decided to discuss our case with a friend who was also a psychologist. He diagnosed the possibility of dementia.

After about six months, Stathis started trembling, yelling and

searching for the right words in order to speak. As a result he became isolated from those who surrounded him. Over the next twelve months, Stathis gradually became unable to write, hold a fork or even eat soup on his own.

Stathis then lost his voice and his ability to eat on his own. He was finally unable to walk. The fact that he still kept contact with reality made him aware of his condition. For this reason he accepted the wheelchair stoically.

Our codes of communication became the tone of his screams and the expressions of his face. By following his look I learned to understand his demands and his needs. I think that my only effective way of making his suffering as easy as possible was by singing to him and hugging him. Stathis died on



Stathis and Anastasia Filipopoulou

the 11th of March 2002. We started together 32 years ago, building our life step by step and hoping to grow old together side by side.

Now, I have to walk alone but full of a love that was offered to me, in abundance, by Stathis, my husband. I have a love to share with people who need me and I am helping them for him.

By Richard Bonwick, consultant psychiatrist at the Austin and Repatriation Medical Centre in Melbourne, Australia

skills to identify an individual's inherent risk of developing dementia. We all carry genetic vulnerability to many illnesses: if we could identify those individuals likely to develop dementia because of their genetic make-up we could focus our efforts on prevention. Findings in this type of research are of particular interest to those with a family history of dementia, and those trying to provide genetic counselling to relatives of people with dementia.

Pathological studies

Pathological studies aim to identify the cause of a dementia, and

thereby shed light on potential treatments, including prevention and possibly even a cure. These studies are probably of most interest to scientists, until they are translated into potential treatments. Treatment studies, of course, are of great interest to people with dementia, their carers, and those treating them. This is probably where the most publicity has been generated in the popular press in recent years, particularly with the successful development and introduction of the cholinesterase inhibitors (galantamine, rivastigmine and donepezil) to treat Alzheimer's disease.

Ethical issues

Debate about the multifactorial ethical issues related to dementia is just beginning to surface in the research literature. These ethical questions are of great importance both to individuals and to those empowered to develop and deliver social policy.

These are the various areas of dementia research I will be reporting on in future issues of Global Perspective.

Members' Forum



Taxi! Alan Jacques, Convenor of Alzheimer Scotland - Action on Dementia, and Susan Frade, Membership and Communications Officer of ADI, hail one of two taxis Alzheimer Scotland hired for a year to publicise their helpline

Scotland

Dementia Awareness Week 2002 marked the launch of a nationwide publicity campaign which aims to increase Alzheimer Scotland – Action on Dementia's profile. The campaign comes in response to the first public opinion poll conducted in Scotland on the extent of public knowledge about dementia. The survey covered attitudes towards people with dementia, personal worries about developing the illness, views on what help is available, and the level of confidence in health and community care services for people with dementia.

The findings included:

- 93% of people recognise the terms 'dementia' and 'Alzheimer's disease' (99% of those over 65 and 85% amongst 16-24 year olds).
- Only 18% of people were able to name Alzheimer Scotland – Action on Dementia as Scotland's national charity supporting people with dementia and their carers.
- One in three people hold misconceptions about dementia. They believe that the illness is a normal part of ageing, that nothing can be

done to help people with dementia, that it 'runs in families', and that the majority of people with dementia in Scotland live in care homes.

- Most people believe that people with dementia could be helped by better professional care, by friends and neighbours, and by drug treatments.

Finland

The Alzheimer Society of Finland has launched a research project looking at how people with dementia and their families adapt to early rehabilitation training. This intervention study aims to identify whether rehabilitation training can increase the length of time a person with dementia remains at home. The research will also try to ascertain the training's cost-effectiveness.

This regional multidisciplinary project is being run in collaboration with researchers from a local university, two university hospitals and a local rehabilitation centre.

Some 300 couples from central and eastern Finland will take part in

the study. A group of 100 couples will be given adaptation training and the remaining couples will form the control group. All couples will be monitored for five years. The results will be used to develop the existing system of dementia care in Finland, gearing its resources towards more productive and cost-effective activities.

Israel

A conference to agree on consensus guidelines for treating people with dementia has been co-ordinated by the Alzheimer's Association of Israel. The guidelines were prepared and agreed by six different committees with representatives from the national organisations of medical doctors, nurses and social workers. The Minister of Health was guest of honour.

Japan

The Alzheimer's Association of Japan has recently launched a new website called 'What is the matter with grandmother?' The site contains six stories about a grandmother, including ones about her family and cat, her missing wallet and misunderstanding her son. The site was designed to help children whose grandparents or parents have dementia understand their behaviour. The association hopes that many children will access the site at home and through school.

Although the site is only available in Japanese, you can visit it at www.alzheimer.or.jp/kodomo and get an idea of its format and design.



PARTNERSHIPS IN ADI

UK and India

A partnership between the West Cumbria Branch of the Alzheimer's Society, the Kottayam Chapter of the Alzheimer's and Related Disorders Society of India and Alzheimer Scotland – Action on Dementia was recently set up by John Chakko, a former carer in West Cumbria. It is called The Link Project.

John, who was born and raised in southern India, was keen to set up a link between his local branch and the Kottayam Chapter. He was also keen to involve Alzheimer Scotland – Action on Dementia as his wife Grace was a Scot. He envisaged the link should provide

opportunities for people involved in the active care of people with dementia to get in touch with one another to exchange ideas, resources and best practice, and to provide mutual support and encouragement.

The West Cumbria Branch was delighted to host a three-day visit in May from Dr Rajani, who is part of a group in Kottayam trying to set up dementia services for people in the area. Dr Rajani visited many different facilities in the branch area – including a local day centre, a residential home, an NHS assessment ward and a support group. She met many different

people involved in dementia care including the two local psycho geriatricians. She also visited ADI before her flight back to India.

First impressions from the West Cumbria branch are that the link has given them a sense of mutual support, and a realisation that they face many issues similar to those faced by the Kottayam Chapter – in particular the importance of raising awareness and the difficulties associated with fundraising. All partners hope the link will be the start of a prospering partnership, which will be strengthened year by year.

EMERGING ALZHEIMER ASSOCIATIONS

Egypt

The work of the Egyptian Alzheimer's Society continues to flourish with branches now set up in six regions, namely Cairo, Alexandria, Assiut, Mansoura, Ismailia and Suez.

The Society's credibility has grown steadily over the last few years throughout Egypt and the authorities now accept the organisation's work. It is moving forward in its work by entering into dialogue with carers to find out what they want. A number of initiatives have been set up in this way – including the production of a regular newsletter, carer support groups and a telephone help line – with varying degrees of success. The most welcomed initiative by family carers has been setting up respite care, which has been developed in partnership with other relevant organisations.

The Society also provides a number of services – including memory clinics, home-based assessments and family support, and bi-monthly family carer training and counselling programmes.



Abdel Moneim Ashour (2nd from left), Chairman of the Egyptian Alzheimer's Association at the launch of the Ismailia branch

In addition to the development of these services, the Society continues with its awareness and education programme and has

found that the consequence of enhanced awareness has been an increased drive to act and achieve on behalf of the Society.

Focusing on people with dementia provides new challenges for Alzheimer's Association Australia

By Glenn Rees, National Executive Director, Alzheimer's Association Australia

It is critical for Alzheimer associations to show that life does not stop with a diagnosis of dementia. As diagnosis gets earlier, we need to be clearer as a society about the value that we put on people with dementia and the contribution that they can make.

As part of our approach to advocacy and awareness, and reducing the stigma of the disease, Alzheimer's Association Australia has reviewed the effectiveness of its existing mechanisms for involving consumers in the life of the Association. The report of the Consumer Focus Project is available at www.alzheimers.org.au

The project was the outcome of recommendations made by a group of people with early stage dementia after our March 2001 National Conference, about how they could be more effectively involved in the work of the Association.

Amongst the main findings of the project were:

- There were no clear lessons to be learned from overseas experience as most Alzheimer associations were still working through similar issues.
- People with dementia were keen to contribute in ways that reflected their skills and previous experience.
- Consumer input was valued by Alzheimer associations, however consultation processes needed to be strengthened.
- Resourcing was seen as restricting consumer involvement.
- Experiences in the disability sector provided some guidance about how people could be supported to undertake a range of roles within the associations.
- There was an opportunity for associations to develop specific

programmes which directly assist people with dementia to remain connected within their own communities and to take up new roles within associations.

- While there were many initiatives which could be developed to increase the participation of consumers, the preference was for an evolutionary rather than a revolutionary approach.

The most effective long-term way of reducing the stigma of the disease and increasing awareness is to involve people with early stage dementia in everyday life. We in Alzheimer's Association Australia recognise that we need to do a lot more to ensure that that happens. We can achieve that goal while recognising the carer origins of our Associations and the vital contribution that carers have made and will continue to make to our work.

Mental health resources fall short of needs

Data collected from government sources by the World Health Organization (WHO) shows a massive gap between what is needed and what is available to take care of people with mental, neurological and behavioural disorders. According to the latest estimates mental, neurological and behavioural disorders together stand at 12.3% of the total disease burden.

The data reveals that 40% of countries have no mental health policies and 25% – including China, Iran, Nigeria, Thailand and Turkey – have no legislation in the field of mental health, though some are in the process of developing legislation. Of the countries reporting, about a third spend less than 1% of their federal health budget on mental health-related activities. Community care facilities have yet to be developed in about half of the countries in the African, Eastern Mediterranean and South-East Asian regions. Of the total number of psychiatric beds in the

world about 65% are still in mental hospitals.

The availability of mental health professionals in large areas of the world is extremely poor. More than 680 million people, the majority of whom are in Africa and Asia, have access to less than one psychiatrist per million of population. One of the surprising findings is that wealthy countries do not always provide the best quantity and quality of mental health resources.

These findings further reinforce the recommendations of the World Health Report 2001 that all countries – large and small, rich and poor – need to give a much higher priority to mental health and take urgent steps to enhance their mental health services.

The data is a useful tool to empower public health institutions and non-governmental organisations in their efforts to influence policy makers. It is available at <http://mh-atlas.ic.gc.ca/>

Living on the other side: dementia and communication

By John Killick



Dementia raises many profound questions about the nature of our humanity, and in this article I want to pose some of them in the words of people with the condition.

Please give me back my personality!

This was said to me by a woman who appeared to be in a state of exasperation about the confused state of her mind. I had had many conversations with her before, and to me she was an individual with very marked traits and positive attitude, yet here she was denying her own personhood. Similarly, many home-carers have said to me that their loved ones had 'gone away'. Yet this was completely at variance with my own impressions.

Something very puzzling seems to be going on here. Maybe the answer lies in differences of perspective. People with dementia are trying to cope with the changes going on inside them, and carers are struggling to adjust to often dramatic alterations in long-term relationships. Yet I am coming from outside and meeting the person as they are now, which is why I am able to see that, despite all the losses that may have occurred, the essence of the person remains.

Who is in charge of the spare words?

Of all the changes that can occur those in communication are often the most marked, especially those in spoken language. The man who

came running towards me urgently calling out this question was clearly troubled by his inability to find the right vocabulary for what he wanted to say. This is an experience we have all had, but not as often or as severely as people with dementia. Because the part of the brain which has been attacked is the one we use for reasoning, this inevitably affects the logical process of word-finding (paradoxically it may also free up the creative use of language, but this is another story). We need to be aware of this, and be ready at all times to offer 'spare words' that may ease the way for the individual.

I've been playing in the house of ages

The woman who said this was surely referring to her memory? This is a subject spoken of by another woman in these words: 'My hiding place now is one I can stretch out to and run away to for a while.' Remembering is being positively referred to here, but we usually think of it in relation to dementia in terms of losses. The spool effect, in which the same memory or question keeps coming round again every two or three minutes, is an example of short-term difficulties, but some people seem to retain very vivid memories of their childhoods. I have observed that often those memories which are accompanied by strong feelings, are the ones with the best chance of survival.

I want to hold and hold you one minute!

We are all using non-verbal means of communication all of the time, though we are often unconscious of the fact. When speech fails the person with dementia, how are they to communicate with us? Maybe, as some have suggested, they become experts in non-verbal means. Of course we still have language to use but could spend more time and effort in meeting people on their own terms – non-verbally. Appealing to the senses can bring great rewards, as the quotation about touch shows. We must not forget, either, that creativity offers many opportunities for expression which don't involve words. One woman said to me 'the arts is all that's left. Give them us!'

I didn't know if you would understand, with you living on the other side

I believe that the key to good dementia care lies in putting communication at the heart of our concerns. Then, and only then, will we begin to answer some of the baffling questions it raises; begin, too, to bridge the gap so that we are all 'living on the same side' as those with the condition.

John Killick is writer in residence for Westminster Health Care in Britain and also Research Fellow in Communication Through the Arts for Dementia Services Development Centre, University of Stirling.

How ADI's 1998 conference changed the face of dementia care in India



It is estimated that there are about four million elderly people in India with dementia. But despite the large number of affected people, dementia was a neglected area of public health in India for many years.

However, this all started to change when the Alzheimer's and Related Disorders Society of India (ARDSI) had the opportunity of hosting ADI's 14th International conference back in 1998 – ADI's first conference in Asia. Cochin, in Kerala, was chosen as the venue because it has the highest life expectancy and highest literacy rate in the country. It is with great pride to everyone in ARDSI that the conference turned out to be a great success, receiving wide media coverage – in fact some leading newspapers brought out special issues to mark the event!

Since hosting the conference, ARDSI's biggest achievement has been the increase in public awareness. When the organisation was set up in 1992, there was not even one service facility available in the whole country. Ten years on, ARDSI now runs three day care centres, a dementia care centre, six memory clinics, community geriatric nursing training programmes and several community care programmes for people with dementia.

Another great achievement has been the acceptance of dementia as a distinct entity by the public and health professionals. In the early

days there was an element of scepticism even on the part of health professionals. Few people were diagnosed. Alzheimer's disease was never a topic at any medical conference. The media were not interested covering anything to do with dementia. Many people even doubted the existence of Alzheimer's disease in India. But this has all changed. Now Alzheimer's disease is one of the topics included by neurologists, psychiatrists, psychologists and general practitioners in their conferences. ARDSI's own national conference is now attended by people from a range of backgrounds.

ADI's conference in 1998 saw the birth of the 10/66 Dementia Research Group. It is amazing to see how fast this group has grown throughout the world. In India, there are more than 10 centres dedicated to dementia research. It is also gratifying to see that the Asia Pacific region, which also had its first meeting in Cochin, has now become a well-established entity under ADI's banner.

ARDSI is growing nationally. Chapters are now being set up in the north and eastern part of India. This year, ARDSI's national conference is being held in Goa, a state which has a significant elderly population with dementia. ARDSI also has also developed many relationships with other Alzheimer's associations – including the

Alzheimer's Society in the UK with which it has an ongoing exchange programme.

Whilst the Indian government hasn't started investing in dementia care or training yet, ARDSI is confident to receive support from the state and central governments in the years to come.

ARDSI's immediate concern is to make the Society self-reliant. Setting up chapters in under-represented areas is a major challenge. ARDSI is also proposing to set up a liaison office in New Delhi soon. In addition, they are also encouraging potential groups in the neighbouring countries to develop Alzheimer's associations. Jacob Roy, chairman of ARDSI said 'We'll continue our efforts until we are able to reach out to each and every person with dementia in India.'

Come to ADI's 18th conference in Barcelona, Spain

23-26 October
Dementia: meeting the challenge together



ADI's annual conference, held in English and Spanish, will bring together researchers, physicians, care providers, staff and volunteers of Alzheimer associations, people with dementia and their families to explore quality of life issues and the global impact of dementia. The conference will also examine the importance of design and architecture in dementia care.

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Web: www.alzheimer2002.com