



# Global Perspective

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

## Helping Alzheimer associations help themselves



Nigeria, Cyprus, Costa Rica and Pakistan learning and sharing from one another



Winners of the fundraising workshop with Martin Horwood, Director of Fundraising for the Alzheimer's Society

**'The Alzheimer University gave me a new look into the aims and objectives of Alzheimer's Pakistan. We cannot do everything. I think for the moment we work towards raising awareness, education and training. I will go back with a better understanding of how to run my organisation.'**

Hussain Jafri, Pakistan

ADI hosted the third 'Alzheimer University' training programme aimed at strengthening the work of emerging Alzheimer associations in London during February. Participants from Costa Rica, Cyprus, India, Indonesia, Nigeria, Pakistan, Peru, Philippines and Ukraine were brought together for a series of workshops designed to help them develop skills to get their associations up and running.

The Alzheimer University focuses on the fundamental issues of setting up an association, such as identifying aims, how to provide information, how to raise awareness and fundraising. The programme ended with a strategy day, consolidating what participants had learnt over the two days and enabling them to set three realistic objectives for their association over the coming year.

ADI's main purpose is to strengthen the work of its members

– stronger Alzheimer associations are better able to meet the needs of people with dementia and their carers. The Alzheimer University is a key activity for working towards this goal.

Participants will be followed up at six months and one year and have been encouraged to keep in regular touch with ADI and each other via an email list.

**'This weekend made me realise that there is nothing more motivating than having clearly stated direction and measurable goals.'** Nilanjana Maulik, India

**'All the topics covered have been useful for our work. In the past, we have spent a lot of time doing things that have not worked well. Now we have learnt some useful tools and will be able to work better.'**

Xinia Jiménez, Costa Rica

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## ANNOUNCEMENTS

2001

5-7 April

### 23rd Alzheimer's Society of Canada's Annual Conference

Halifax, Canada  
Tel: +1 416 488 8772  
Fax: +1 416 488 3778  
Email: education@alzheimers.ca  
Web: www.alzheimer.ca

18-19 April

### 1st International Conference on Alzheimer's Disease and Related Disorders in the Middle East

Limassol, Cyprus  
Tel: +1 216 368 1912  
Fax: +1 216 368 1989  
Email: rpf2@po.cwru.edu

23-27 April

### 5th Society of Neuroscientists of Africa conference

Nairobi, Kenya  
Tel: +254 2 442 309  
Fax: +254 2 750 154  
Email: nbpatel@form-net.com  
Web: www.uonbi.ac.ke/news\_adverts

7-10 May

### 4th Latin American Regional Meeting

Montevideo, Uruguay  
Tel/Fax: +598 2 400 87 97  
Email: audasur@adinet.com.uy

22-25 May

### European Society for Neurochemistry Advances in Molecular Mechanisms of Neurological Disorders

Perugia, Italy  
Tel/Fax: +39 075 5857420  
Email: goracci@unipg.it  
Web: bioingweb.dimisem.med.unipg.it/esn2001

9-12 June

### 11th Alzheimer Europe Conference

Beyond the old borders  
Bucharest, Romania  
Tel/fax: +40 1 410 5308  
Email: alzheimereurocong@infomedica.ro  
Web: www.alzheimer-conference.org

17-22 June

### XVIIth World Congress of Neurology

London, UK  
Tel: +44 20 8743 3106  
Fax: +44 20 8743 1010  
E-mail: wcn@concorde-uk.com  
Web: www.concorde-uk.com/wcn-2001

25-27 October 2001

## 17th Alzheimer's Disease International Conference

Partnerships in Dementia Care

Christchurch, New Zealand  
Tel: +64 3 364 2534  
Fax: +64 3 364 2057  
Email: alz@cont.canterbury.ac.nz  
Web: www.conference.canterbury.ac.nz/alzheimer2001

28 June-1 July

### 5th International Care/Case Management Conference

Care/Case: Who Needs it?  
Vancouver, Canada  
Tel: +1 415 974 9600  
Fax: +1 415 974 0300  
Email: info@asaging.org  
Web: www.asaging.org/icm

29 June-1 July

### 4th Conference of the International Association of Homes & Services for the Ageing

One World, Diverse Approaches to Housing and Care  
Vancouver, Canada  
Fax: +1 202 783 2255  
Email: iaahsa@aahsa.org  
Web: www.aahsa.org/iahsa

1-6 July

### International Association of Gerontology's 17th World Congress

Vancouver, Canada  
Tel: +1 604 291 5062  
Fax: +1 604 291 5066  
Email: iag@sfu.ca  
Web: www.harbour.sfu.ca/iag

15-18 July

### 10th National Alzheimer's Disease Education Conference

New Directions in Alzheimer Care  
Chicago, USA  
Tel: +1 312 335 5790  
Web: www.alz.org

9-14 September

### 10th IPA International Congress

Bridging the gap between brain and mind  
Nice, France  
Tel: +33 4 93 92 81 61  
Fax: +33 4 93 92 83 38  
Email: ipa2001@nice-acropolis.com

4-7 October

### 2nd International Congress on Vascular Dementia

Paphos, Cyprus  
Tel: +972 3 514 0000  
Fax: +972 3 514 0077  
Email: vascular@kenes.com

## PUBLICATIONS

Due to an increase in demand for ADI publications, it has been necessary to introduce charges for the bulk order of our materials. Please contact the secretariat for more details.

### Alzheimer's At Your Fingertips

By Harry Cayton, Dr Nori Graham and Dr James Warner. Clear and helpful answers to all your questions about Alzheimer's disease and other forms of dementia.  
£14.95 available from Class Publishing, London W6 7BR, UK (tel +44 (0)1752 202301; fax: +44 (0)1752 202333; web: www.class.co.uk).

### Managing Alzheimer's Disease in Primary Care

By Henry Brodaty. £12.95 available from Plymbridge Distributors, Estover Road, Plymouth, Devon, PL6 7PZ, UK (Tel: +44 (0)1752 202 301; Fax: +44 (0)1752 202 331; web: www.plymbridge.com. Please quote ISBN: 1-85873-312-X).

### Alzheimer's Disease in Primary Care Second Edition

By Serge Gauthier. £9.95 available from Martin Dunitz Publishers, The Livery House, 7-9 Pratt Street, London NW1 0AE (Tel: +44 (0)20 7482 2202, fax: +44 (0)20 7482 7088, web: www.dunitz.co.uk)

### Decoding Darkness: The Search for the Genetic Causes of Alzheimer's Disease

By Rudolph E. Tanzi and Ann B. Parsons  
£15.95 available from Plymbridge Distributors, Estover Road, Plymouth PL6 7PZ, UK (Tel: +44 (0)1752 202 301; Fax: +44 (0)1752 202 331; web: www.plymbridge.com. Please quote ISBN: 0-7382-0195-2)



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#### Mailing list

If you would like to receive this newsletter, please give the Secretariat your details. There is no charge, but donations are always welcome.

#### Send us your comments

If you have any comments about or items for the newsletter (we are particularly keen to hear from carers) please contact the Secretariat.

#### Put your requests for help in Members' Forum

Member countries requiring help or information are asked to put their requests in writing for inclusion in Global Perspective.



# Nanna

By Blair Dunstan (aged 11 years), Australia

Mum and I have made many sacrifices to look after my Nanna. We have to share a lounge and an air mattress, as my Nanna's house is small. All my possessions are in storage: these things I miss.

I can't have my friends over to play or sleep because it would really stress Nanna out and embarrass me because she would always be complaining about the noise and acting agitated.

She often asks where her husband is. It is very sad because we have to tell her he is in heaven. This brings tears to her eyes. She comes back down and asks five minutes later the same question. I have to just stand there, watching her cry quietly to herself. Mum and I try to comfort her but she just walks over to the window and sits down, gazing outside.

I often wonder what is going through her mind. She sometimes calls me by my uncle's name, which is Grant. My Nanna knows what she wants to say but it sometimes

comes out differently. I often help Nanna and make her cups of tea and pancakes, which she enjoys.

I find it hard to do my homework at times as Nanna often distracts me with her repetitive questions. Working in this environment can sometimes be impossible. This is why I sometimes get my homework in late.

Living at my Nanna's can be rewarding though. My Nanna turned 90 years old on the 10th June 2000. By what you've heard you probably think she's a very cranky and disturbed lady, but you're wrong. She is a very happy, cheerful lady who also enjoys a good joke.

Sometimes when my mum and I are out doing the shopping or walking our dog, etc, we have carers to come and comfort Nanna. They often make her lunch or take her for a drive. They also do some chores for my Nanna as well.

All the carers say that she's a very cheerful and jolly lady. Mum, Nanna and I have met a lot of very

nice carers. Some from Ireland, England or America, but most of them are Aussies.

The reason we moved into our Nanna's is so that we can give her some moral support and a sense of security. She often wandered outside at dusk. This is not safe to do these days as the elderly are vulnerable targets.

You are probably wondering why we have the responsibility of caring for my Nanna. Well my Nanna lost her only child (my Mum's dad) when my Mum was 5 years old.

Now my Nanna is in need of some one to care for her, we are now returning the kind gesture. When I look back to this time in the future I will feel proud of the respect, love and kindness that my Nanna gave me and the great experience I shared and learned from my Nanna. I will know that I contributed to the fulfilment of my Nanna's life.

We know our Nanna won't be with us forever: so it is good that we have had this experience. You may think we are crazy, but we love having our Nanna around and hope she lives on for a very long time. I will cherish these moments forever.

## Home for help exchange

**Homeshare** is the exchange of housing for help. It recognises that two people have needs and something to give. It works by a householder offering accommodation to a homesharer in exchange for an agreed level of support. The householder may need help with household tasks or income from a modest rent, or a combination of both.

Homeshare is a very flexible concept. It can meet many needs and be adapted to different countries, cultures and circumstances and brings benefits to both parties.



For example older or disabled households can get help with tasks like shopping or preparing meals. Many value companionship and the security of someone in the house,

especially at night. Homesharing can help older or disabled people remain independent. Research from the programme in Germany has shown that older people will accept help from their homesharer because they are getting something in return.

The first Homeshare programme was founded in the USA in 1972. Now it is running in eight countries: Australia, Austria, Canada, Czech Republic, Germany, Spain, UK and USA. If you would like to find out more about the programme or know of a programme in another country, contact: Nan Maitland, Homeshare International, 54 Christchurch Street, London, SW3 4AR, UK; fax: +44 (0)20 7349 0444; email [HI@homeshare.org](mailto:HI@homeshare.org)

# Members' Forum

## AUSTRALIA

Good news for Australians as the Department of Health announced just before Christmas they are subsidising Aricept and Exelon. This announcement comes after a three-year campaign in which the Alzheimer's Association of Australia, families of people with Alzheimer's disease and professionals joined forces in a bid to make these drugs available at a reduced cost.

## KOREA

The Alzheimer's Association of Korea have recently embarked on an activity programme for caregivers – giving them the opportunity to relax and share information away from their support group. About 40 people took the opportunity to visit a hot spring just outside of Seoul, the capital. Some branch office directors also joined the trip and

were able to share their professional, as well as personal experiences of dementia.

Sunghee Lee, the association's chairperson, had been planning a stress-relief get away break for some years and was delighted by how much the caregivers appreciated the day. She is now planning an overnight trip.

## UK

Good news too in the UK as the National Institute for Clinical Excellent (NICE) has recommended that the National Health Service should fund access to the drugs for Alzheimer's disease.

NICE, a government body set up to put an end to the difficulty faced by people in some areas gaining access to treatments available elsewhere in the country, gathered evidence from the Alzheimer's Society, pharmaceutical compa-

nies, independent experts in clinical trials, health economists and clinicians. The Society submitted contributions from hundreds of people with dementia and their carers.

While the NICE recommendation is not binding, health authorities will come under pressure to provide adequate funding for the three licensed medicines currently available in the UK.

## TRINIDAD AND TOBAGO

Congratulations to the Alzheimer's Association of Trinidad and Tobago who persuaded Nori Graham, chairman of ADI, to take time out from her holiday on the island last December and formally launch their association! Trinidad and Tobago participated in ADI's second Alzheimer University and since then have addressed some basic issues such as setting up a membership database and support groups outside the capital Port of Spain. They are now planning a telephone helpline.

## EMERGING ALZHEIMER'S ASSOCIATIONS

### CURACAO ALZHEIMER'S FOUNDATION

World Alzheimer's Day 2000 saw the launch of the Curaçao Alzheimer's Foundation first symposium, which was officially opened by the governor of the Netherlands Antilles. The day was a great success and over 450 people from the community came to hear presentations on current research, practical tips on how to care at home, the rights of the person with dementia and information about why it is important to sort out legal and financial matters early. The day ended with a lively panel discussion.

During the evening, the commissioner of a telecommunications company inaugurated the

Foundation's hotline. The hotline is open for information and advice every Wednesday from 0800-1200.

The Curaçao Alzheimer's Foundation was officially established in March 2000 and aims to:

- Disseminate information about dementia
- Improve care for people with dementia
- Give practical information and support to the families of those affected

The Foundation strives to achieve these goals by organising lectures and workshops for medical professionals as well as the families of people with dementia.

Plans for the coming year include publishing folders for students and caregivers, as well as organising workshops for fami-

lies and caregivers. With the support of the private sector, the Foundation hopes to organise a similar symposium on Bonaire and St. Maarten, islands in the same archipelago.

### GUYANA

The Alzheimer's Association of Guyana also used this year's World Alzheimer's Day to launch the work of their association. They organised a seminar in the capital Georgetown. The association has just completed its development plans, which includes the formation and training of a support group and the intention to co-ordinate an event for World Health Day (7 April 2001).

# Partnerships in ADI

## SINGAPORE/MALAYSIA

A recent fact-finding visit to Singapore's Alzheimer's Care Centre project by the Alzheimer's Disease Foundation Malaysia (ADFM) proved immensely productive. ADFM have been looking at the possibility of opening such a centre but have also been asking themselves whether the high set-up and operational costs are justifiable. To extend the benefits of the project, the centre would also be used as a model to encourage and facilitate the setting up of other dementia care facilities in the public, commercial and voluntary sectors, as well as provide dementia care training for family caregivers, domestic help, healthcare workers and volunteers.

These noble objectives looked good on paper, but could ADFM make them work?

Discussions with Dr. Ang Peng Chye, chairman of the Alzheimer's Association of Singapore dispelled



Staff of the New Horizon Centre show Kheng Leng (fourth from left) and Kong Voon Sin (fifth from left) around the centre

their doubts. He explained how the day centre in Singapore facilitated hands-on dementia care training for nursing home staff, leading to nursing homes opening their doors to people with dementia. The increase in awareness also resulted in more day centres and nursing homes being set up, not only by the association but also by other non-governmental organizations.

There was an opportunity to visit a second nursing home complex specialising in dementia care with its own attendant nursing staff. Whilst this centre was further from the city and therefore more spacious, it also made it less accessible to potential users.

ADFM also met with the Tsao Foundation to plan a train-the-trainers course in Malaysia later this year leaving a core batch of trainers to spur the development of dementia care in Malaysia

The visit has given ADFM greater confidence that they are moving in the right direction and renewed their commitment to the ACC project. ADFM look forward to new beginnings in the development of the Alzheimer's movement in Malaysia and to many more years of co-operation with their friends in Singapore!

*For more information contact Kheng Leng Chew at [alzheimers@pd.jaring.my](mailto:alzheimers@pd.jaring.my)*

## CHILE/CUBA

### Chile and Cuba cooperate on training programme for nurses

Julieta Montebruno of the Alzheimer's Association of Chile, a

nurse by profession and volunteer for the Alzheimer's Association, visited Cuba in December to run a training programme on dementia

for primary care nurses working with older adults in Havana. The course was held in a district of Havana where there is a large population of older people. 23 primary care nurses attended along with 3 doctors.

One of the objectives of the course was training in the early detection of dementia in the primary care setting. The nurses were trained in the use of simple tools which could either be used on a domiciliary visit or in the office. The importance of training family caregivers was also emphasised as the majority of people with dementia are cared for at home. The evaluation of the course was encouraging and it is hoped to develop it further for other Latin American countries.



Julieta Montebruno (second from right) with Juan de Llibre Rodriguez (third from left), president of the Cuban Alzheimer Association

# Diagnosing dementia: the first step to help

**World Alzheimer's Day 2001**

The theme for this year's World Alzheimer's Day centres around the importance of having a diagnosis of dementia. Naming a person's symptoms helps to demystify or destigmatise their condition and may also resolve their anxiety, as well as that of their family. It can maximise a person's quality of life, give a person a greater chance of benefiting from existing treatments, allows the person with dementia

and their family access to resources and information, and provides more time to plan for the future.

It is a common assumption that making a diagnosis involves a series of expensive, hi-tech clinical investigations. This is not true for dementia where the most important part of diagnosis is listening to the person's story of the development of dementia. Examination of the person includes a simple cognitive

assessment. Dementia diagnosis measures are now available in the main Indian languages, Mandarin, Cantonese, Spanish, Portuguese as well as the other main European languages – a reflection that dementia is becoming a recognised condition throughout the world.

Currently there are 18 million people in the world with dementia, of which about 66% live in developing countries. As the world's population ages and the numbers of people being diagnosed with dementia increases, more people will be turning to Alzheimer's associations for help. Alzheimer's associations are dedicated to providing support to people with dementia and their families.

Please contact the secretariat if you would like to order materials to organise an event for this year's World Alzheimer's Day. Alternatively, why not contact your Alzheimer's associations' national office or local chapter/branch and find out what they are planning to do.

ADI, 45/46 Lower Marsh, London, SE1 7RG, UK; tel: +44 (0)20 7620 3011; fax: +44 (0)20 7401 7351; email [adi@alz.co.uk](mailto:adi@alz.co.uk); web: [www.alz.co.uk](http://www.alz.co.uk)



Costa Rica celebrating their first ever public meeting on Alzheimer's disease during World Alzheimer's Day 2000



For more information about the International Year of Volunteers visit the website [www.iyv.org](http://www.iyv.org)

## International Year of Volunteers

Voluntary service has been a part of virtually every civilization and society. Defined as a non-profit, non-wage and non-career action that individuals carry out for the well-being of their neighbours, community or society at large, volunteering takes many forms from traditional customs of mutual self-help to community responses in times of crisis and effort for relief, conflict resolution and the eradication of poverty.

In November 1997, the United Nations General Assembly proclaimed 2001 as the International Year of Volunteers. With its main objectives of

increased recognition, facilitation, networking and promotion of volunteering, the International Year of Volunteers 2001 (IYV) provides a unique opportunity to highlight the achievements of the millions of volunteers worldwide and to encourage more people globally to engage in volunteer activity.

Why not consider volunteering for the Alzheimer's association in your country? Most associations are reliant on volunteers to achieve their aims. If you would like details of the Alzheimer's association in your country, contact the ADI secretariat.

# Ministers and myths

## Dementia attitudes in Nigeria

**Richard Uwakwe**

Psychiatrist, Nnamdi Azikiwe University Teaching Hospital, Anambra State, Nigeria. Chairman and founder of Alzheimer's Association of Nigeria

Although many developing countries are experiencing an increase in the number of people with dementia, they do not benefit from the recent pharmacological, psychological and social developments in the care arrangements for people with dementia. In Nigeria, for example, mental health services have not been fully developed and accepted by the general population resulting in many people with dementia seeking alternative services – mainly religious and (folk) healing.

A recent study carried out in Anambra, Nigeria, assessed, among other things, religious organisations knowledge about dementia, including their role in the care of people with dementia.

Ten religious ministers, whose congregation included people with dementia who had dropped out of hospital treatment, were interviewed to determine their knowledge, attitude and practice of dementia. All ten ministers believed dementia occurs when an evil spirit through demonic attack (by witches or wizards) possesses the brain leading to loss of memory, bad dreams, hallucinations and irrational talk. Treatments used by churches include fasting, special prayers, saying the rosary, penance, reading specific portions of the Bible, home visits, beating, exorcism, crusades, night vigils, testimonies, music and dancing.

With the explosion of Pentecostal churches throughout Nigeria, religious healing has become a popular intervention and the church has become an important place for



Helping change attitudes; the Alzheimer Association of Nigeria

the study of mental health services for people with dementia. With such an influence, it is important that religious leaders be educated, correcting any misconceptions that have led to the use of dangerous treatment methods such as beating.

Music and dancing are in the core of African culture and tradition contributing greatly to Africans motivation. In addition, they are excellent group psychotherapeutic techniques, providing relaxation and exercise, as well as reminiscence therapy. Perhaps the lack of music and dance in Nigeria's traditional care arrangements together with the lack of a group setting may partly account for the under use of hospital services and it may be necessary and practical to incorporate these into future care arrangements. As fewer family members

are available to care for people with dementia, it is church members who are able to mobilise as well organise volunteers to pay home visits, provide daily care, respite care, befriending and other services.

There are no social security provisions for elderly people and as the traditional extended family set up gradually disintegrates, many Nigerians are now being left to themselves, such that people with dementia require enormous outside assistance which the church can be mobilised to provide. If this church assistance is combined with greater acceptance of western care, modified to accommodate the relevant religious and cultural practices of Africans, it may be possible to develop better dementia services in Nigeria.

## Vaccine investigation

Research published in the journal *Nature* on 21 December 2000, indicated that a vaccine is in development which could prevent the build up of protein deposits (plaques) in the brain, and halt the symptoms of dementia. The research carried out in mice, which had been genetically engineered to mimic Alzheimer's disease, showed that damage to their brain cells was reversed and

their memories appeared to be restored. Although the research was based on mice, small-scale human trials are now in progress. However, these will have to be replicated on a much greater scale before a vaccine is available to the public.

For more information about the vaccine, visit [www.nature.com/nature/fow/001221.html](http://www.nature.com/nature/fow/001221.html)

ADI's 17th annual conference

# Partnerships in dementia care

Join the Alzheimer's Society of New Zealand, hosts of ADI's 17th annual conference in Christchurch during 25-27 October 2001, for the first major international conference on dementia held in New Zealand. The theme of this meeting is 'partnerships in dementia care'.

The conference provides a unique opportunity to present a New Zealand focus on developing and debating partnerships in dementia care alongside the expertise and knowledge of world-renowned health professionals. The three days will look at: Partnerships among cultures including a Maori perspective; partnerships between research and caregiving; and partnerships in delivery of care.

The Alzheimer's Society of New Zealand national office was set up in 1983 in Canterbury and is now supported by 22 autonomous groups throughout New Zealand's two islands. Local groups provide advice and counselling, home visits and sitting services, groups for people in the early stages of dementia, carer education and

The second announcement gives full details of the programme



dementia training amongst other services for the estimated 38,000 people with dementia.

Partnership in dementia care is not a new concept to the Society who has played a crucial role in the establishment of dementia care and education of health professionals. The Ministry of Health contracts the Alzheimer's Society of New Zealand to provide dementia care and services to the people of New Zealand. One of the challenges facing the association is the lack of awareness, medical support and care facilities in rural areas. With a population density of 13 people per square metre (compared to 230 in the UK), field officers often cover large areas and getting to people takes up much of their day. Other issues for the rural community include access to appropriate care facilities, the lack of like-minded people to set up support groups and services for younger people with dementia.

If you are working towards a better understanding of dementia and the support of people with dementia, why not consider attending? For more information about the conference, visit the website [www.conference.canterbury.ac.nz/alzheimer2001](http://www.conference.canterbury.ac.nz/alzheimer2001) or fax +64 3 364 2057

## Stop exclusion – dare to care

World Health Day  
7 April 2001



In a bid to focus on the stigma and discrimination surrounding mental health, the World Health Organization (WHO) launched a year-long campaign on mental health, including Alzheimer's disease and other dementias. WHO is daring governments, health professionals and people from all walks of life to rise to the challenge posed by mental and brain disorders.

World Health Day 2001, with the slogan 'Stop exclusion – dare to care' aims not only to raise awareness about barriers to mental health but also about solutions that exist to tackle mental and brain disorders.

The issue will be put before the annual gathering of WHO's 191 Member States during the World Health Assembly (WHA) in May 2001. The World Health Report 2001, scheduled for release later this year, will highlight the prevalence of mental health disorders, the organisation and financing of mental health programmes, treatment gaps, prevention strategies and projected future trends.

ADI is actively participating in World Health Day, Nori Graham will be speaking in Geneva on April 6 for the official launch and ADI will have the exciting opportunity to address the World Health Assembly in May on the global challenges of dementia.

'We must strive for uniformity in the way mental and physical disorders are regarded. We know what is wrong, we know where the solutions lie. We have a responsibility to push for changes in both policy and attitude and we are determined to do just that' said Dr Saraceno, Director of WHO's Mental Health Programme.

For more information see [www.who.org](http://www.who.org)