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Alzheimer's Disease
International

JULY 2001

Global Perspective

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

Stop exclusion. Dare to care

Dr Gro Harlem Brundtland, Director General of WHO, launched World Health Day

Mental health was selected by the World Health Organization (WHO) as the theme for World Health Day 7 April 2001. Six representative disorders, including Alzheimer's disease, were highlighted. Focusing on the stigma and discrimination surrounding mental health, WHO is daring governments, health professionals and people from all walks of life to rise to the challenge posed by mental and brain disorders.

ADI was invited to deliver a statement at the official launch of World Health Day on 6 April in Geneva. Nori Graham, Chairman of ADI, took this opportunity to say, 'The great majority of people with dementia are doubly excluded, both because they are old and because they they have lost their memories and are regarded as useless and a nuisance. This is no way for people to end their lives. Those who care for people with dementia are also excluded from society because they do not have the time or money to enjoy a social existence. This need not happen.'

Turn to page 7 to see how World Health Day was observed by some ADI members. Read Nori Graham's full speech at www.alz.co.uk

A warm welcome awaits in New Zealand

On behalf of the conference organising committees, I have great pleasure in inviting you to attend the 17th Alzheimer's Disease International conference, to be held in the beautiful garden city of Christchurch. We have been busy planning a comprehensive programme which will ensure that the momentum created in Washington at the very successful World Alzheimer Congress 2000 will be continued. We feel honoured by the impressive array of international speakers, all experts in their field, who have agreed to join us in October to share their knowledge and experience. Some delegates will need to travel great distances to reach our shores, but we can assure you that your journey will be well worthwhile. It will provide you with the opportunity to learn of the latest developments in dementia care, and also allow you to spend precious time with old friends, to meet new ones and to share with all delegates in the common goal of improving life for the person with dementia.

Registration brochures are now available. For more information visit www.conference.canterbury.ac.nz/alzheimer2001

Wendy Fleming, Conference Chairperson, invites you to Christchurch, New Zealand 25-27 October 2001

IN THIS ISSUE

Website address: http://www.alz.co.uk Email: adi@alz.co.uk

ANNOUNCEMENTS AND CONFERENCES

2001

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
Web: www.kenes.com/vascular

25-27 October
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

14-15 December
International College of Geriatric Psychoneuropharmacology
Hawaii, USA
Tel: +1 615 322 4247
Fax: +1 615 322 4246
Email: oray@icgp.org

2002

17-20 April
IPA European and Mediterranean Regional Meeting
The Qualities of Aging
Rome, Italy
Tel: +1 847 784 1701
Fax: + 1 847 784 1705
Email: ipa@ipa-online.org
Web: www.ipa-online.org

27-30 April
14th Annual Public Policy Forum
Washington DC, USA
Tel: +1 2002 393 7737
Fax: +1 202 393 2109

20-25 July
8th International Conference on Alzheimer's Disease and Related Disorders
Stockholm, Sweden
Tel: +1 312 335 5813
Fax: +1 312 335 5781
Web: www.alz.org/internationalconference

PUBLICATIONS

Management of Dementia
By Simon Lovestone and Serge Gauthier
£24.95 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)

Who will I be when I die?
By Christine Boden
Available from www.collinsbooks.com.au
ISBN 186 371 7331

Elder Rage
By Jacqueline Marcell
Available from Tel: +1 949 975 1012; fax: +1 949 975 1013; web www.ElderRage.com

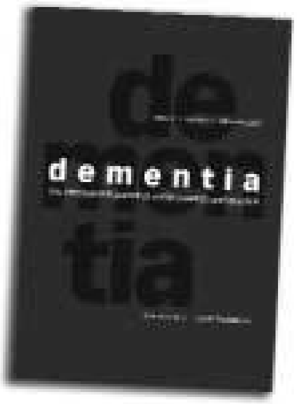
Quel jour sommes nous? La maladie d'Alzheimer jour après jour
By Firmin Le Bourhis
Published by Editions Chiron, Paris
See review below

REVIEW by Gillian Tindall

Quel jour sommes nous? La maladie d'Alzheimer jour après jour by Firmin Le Bourhis

Sylvie and Alan are in their forties and run a clothing factory in Brittany. They are happily married, their quality of life is high; they even have a devoted old nanny about the house. Then, insidiously, Sylvie begins to seem over-strained, she has memory lapses, then moments of inappropriate behaviour … inexorably, step by carefully charted step, she descends into the cellar of the mind from which there is no way up again. Any reader of French who has been witness to a comparable descent, or fears to be, will find the essential documentary content of this short novel authentic and, if not exactly comforting, absorbing and moving.

New journal from Sage Publications in February 2002!



Dementia: The International Journal of Social Research and Practice
Editors: John Keady, University of Wales, Bangor, UK and Phyllis Braudy Harris, John Carroll University, USA

Published 3 times a year, *Dementia: The international Journal of Social Research and Practice* will provide an exciting step forward for the field of dementia care generally, and social research specifically. The journal will act as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families. For the first time an international research journal will be available for academics and practitioners that has as its paradigm the lived experience of dementia.

For more information about contributing and subscribing to the journal, please visit the Sage website: www.sagepub.co.uk and go to the journals section.

Global Perspective

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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.

from the heart

My dad

by Lauren West, UK

That's what really hurts – seeing my Dad, who I loved so much, change into someone I hardly know

When I was told my Dad had Alzheimer's I didn't know what to think. I suppose this was because I didn't really know much about the disease.

It wasn't long after he was diagnosed that nurses were in and out of the house and that's when I knew that things were going to have a big effect on our family. I remember Mum telling me that the changes in Dad would be permanent. I took in what she said but deep down I had a tiny bit of hope that what she was saying wouldn't happen and everything would soon go back to normal. I couldn't have been more wrong.

Dad's illness didn't happen overnight. I think it's been in the last couple of years that changes in his behaviour have been a lot more noticeable. Dad struggles with simple tasks such as getting washed and dressed. I normally help him when it comes to his bedtime. Although I don't mind I find it really hard. I think this is because Dad used to put me to bed when I was little but now he's not capable of doing this for himself.

It's a shame really because he was such an intelligent man. He taught me to say my alphabet backwards and, if I ever had problems with maths homework, Dad was the one to go to. He used to nag me to work hard at school, as he wanted me to get good grades at my GCSEs. I've recently got my results and, although Dad didn't take it in when I told him, I know that he would have been proud of me.

The Dad I now have is not who he was before. He may look the same but it seems as though he's a different person. I suppose that's what really hurts – seeing my Dad, who I loved so much, change into someone I hardly know. It's strange because although he is still with us it's as if he isn't. I used to go to bed thinking that when I woke up the old Dad would be back with us. Instead it's as though we're living with a stranger.

People keep saying that I should be grateful that he is still alive, but I believe in my heart that my Dad died a long time ago. Although he's still here, his mind isn't. That Dad I once had has now gone and I miss him.

The last year has been a struggle. If things start to get too much I think of the old times. I will always have my memories and these are something which I will hold on to for the rest of my life.

I find it easier to talk about Dad with my family rather than my friends. They try to understand but I think they find it hard to talk about so I normally keep how I'm feeling to myself. My friends often ask me, 'How's your Dad?' I never really know how to answer. He will never be better and will get worse. That's what they find hard to come to terms with. It took me a long time to get used to the situation myself.

I think it will be hard when Dad goes into full time care but, in the long run, it will be for the best – not just for us but for Dad as well.

Dad once said to me that when I'm older, if I have a boy, could I name him Laurence after him. I remember at the time smiling as I didn't really think much of it. Now, though, I probably will because I know it would be something I could do that would have made Dad proud.

Members' Forum

CYPRUS

Limassol, 17-19 April, was the venue for the first international symposium on Alzheimer's disease in the Middle East where over 100 dementia experts came together.

Mr Frixos Savvides, the Cyprus Minister of Health, opened the meeting with a promise to help people with dementia and their families, and give further support to NGOs working in this field. Nori Graham, chairman of ADI, then described the global efforts of ADI to exert continuing pressure on governments and other authorities in order to recognise the needs of people with dementia and their families and act appropriately.

During the meeting, emphasis was given to epidemiological research suggesting that certain Middle Eastern populations have a higher than average prevalence of Alzheimer's disease. This, together with the increase of life expectancy, should alert governments and health care providers to plan for appropriate solutions.

Nori Graham also chaired a session in which carers shared their experiences on caring for a person with dementia. In this session, Georgia Iosifidou described the Alzheimer Association of Cyprus' efforts over the last five years to raise public awareness and convince the government to make drug treatments for Alzheimer's disease available free of charge, establish day care centres and strengthen existing day care services. Ruth Goldberg also described the successful programmes of the Alzheimer's Association of Israel.

Preparations are now under way for the region's 2nd international symposium.

Nori Graham, far right, joins the Alzheimer Association of Cyprus

USA

A fond farewell to Edward Truschke, President and CEO of the Alzheimer's Association, who retired earlier this year. Ed had been with the association since it was set up in 1980 and was also involved in the founding of ADI back in 1984. He has always been extremely supportive of ADI. Alan Stone has been appointed the new President and CEO.

A prescription for change

Nearly 500 Alzheimer advocates, caregivers, individuals with dementia and staff of the Alzheimer's Association (USA) from around the country united in Washington DC in April for the association's annual Public Policy Forum.

The forum provides an opportunity to hear the latest in research, learn more about issues ranging from long term care task forces to affordable assisted living, and listen to people with dementia talk about their illness in their own words.

The forum concluded with a day on Capitol Hill where advocates attended a Congressional hearing on Alzheimer's disease and met with their legislators. Advocates carried with them to these meetings a prescription for change that included the Association's one billion dollar research goal, messages about improving caregiver support and the need for Medicare prescription drug coverage.

PERU

After participating in the Alzheimer University earlier this year, Mariella Guerra (back row, 2nd right) and Margarita Olivares (back row, 5th from right) have repeated the course to their fellow board members and those on the board of the branch in Arequipa, the second largest city in Peru. Having gained so much from the course, they wanted to share their knowledge and experiences to strengthen the work of the Alzheimer association in Peru.

REGIONAL MEETINGS

URUGUAY

(LEFT TO RIGHT) **Nori Graham, Roberto Ventura (Uruguay) and Roberto Garcia (Mexico) in Montevideo**

Congratulations to AUDAS for hosting the 4th Latin American regional meeting in Montevideo during March, which also coincided with their 10th anniversary celebrations. Eleven of ADI's Latin American members participated in the meeting, using the opportunity of being together to run workshops in Spanish on the role of the board and coping with growth.

ROMANIA

'Beyond Old Borders' was the theme of this year's Alzheimer Europe meeting hosted by the Alzheimer's Society of Romania in Bucharest. Catalina Tudose, Chairperson of the Society, described how miraculous and extraordinary it was to host this meeting in a country where up until 11 years ago there were no words to describe dementia nor how to help people with dementia.

Verna Schofield (centre) with Alan Jacques (Convenor of Alzheimer Scotland - Action on dementia) and Christine McGregor (Vice Convenor of Alzheimer Scotland – Action on Dementia)

The meeting was also an excellent opportunity for Verna Schofield from New Zealand, who is on ADI's executive committee, to meet with other individuals on the ADI working group looking at preparing regional guidelines for ADI.

PARTNERSHIPS IN ADI

India and UK

A staff exchange programme between the UK's Alzheimer's Society and the Alzheimer's and Related Disorders Society India (ARDSI) was initiated during ADI's 1998 conference hosted by ARDSI in Cochin, India. The programme started with two members of ARDSI coming over to London to learn about the Society's work and participate at the 'A Meeting of Minds' conference which also celebrated the Society's 20th anniversary in 1999. This initial visit was followed with two members of Society visiting India.

This year, the Society has supported Nilanjana Maulik and Mathew Kanamala from ARDSI, to come to the UK. After returning home Nilanjana reflected on what the exchange meant to her. 'The Alzheimer Society gave us an excellent opportunity of seeing services in action by arranging visits to day care settings, regional offices and committee meetings. It was a wonderful way to get an understanding of the way the Society analyses, evaluates and strives to improve services. Our visit coincided with ADI's Alzheimer University programme and the Society's two-yearly annual staff conference, during which I presented a paper discussing various aspects of dementia in India, including prevalence and support services. I had a very interactive session with lots of questions and also collected ideas and suggestions from the audience to implement back home.

'Participating with diverse communities and planning together can be a very powerful experience. This was true of this collaboration, which was mutually beneficial as it helped us gather key issues and concerns to explore possible new initiatives, understand our ability to work effectively in groups/teams and develop an attitude that instills self-awareness, commitment to lifelong learning and openness to change. I am very sure that this exchange of ideas will help us to think differently and make wiser choices in our future endeavors.'

Listening and learning at the Alzheimer University. Nilanjana (right) and Antigoni Diakou from Cyprus

PARTNERSHIPS IN ADI CONTINUED ON NEXT PAGE…

Nordic Alliance

Clara Lindeman, chairperson of Jakobstadsnehdens Alzheimerfrening celebrates the chapter's 10th anniversary with Pekka Laine, Chairman of Alzheimer Society of Finland at the Nordic Alliance meeting

Alzheimer associations from Denmark, Finland, Iceland, Norway, Sweden and Åland have cooperated quite closely for a number of years and meet formally on an annual basis. The group's meeting in 1999 culminated in the signing of the 'Kalmar declaration' – a ten point declaration requesting the Nordic governments and Nordic Council to pay serious attention to issues related to dementia. The declaration resulted in the Nordic Council suggesting that its ministers take measures to ensure better dementia care in the region. The suggestions included closer collaboration on related cross-scientific research, adoption and implementation of clear dementia care philosophies, better support for family carers of people with dementia and coordination of education programmes.

The meeting in 2000 initiated discussions on issues related to housing people with dementia which were continued this year in Finland. There has been wide and lively discussions in Finland recently regarding the quality of Finnish dementia care, which up until now has been heavily institutional based. For this reason, the Alzheimer Society of Finland now feels the need to discuss how to create services that appropriately support people with dementia and their carers. Discussions on the issues related to housing will be continued at the group's next meeting in Denmark 2002. In the meantime a working group is preparing a project to identify new housing solutions for municipalities to carry out good dementia care. The Nordic Council of Ministers is supporting the project.

Black and minority ethnic community project

It is estimated that nearly half of the UK's black and minority ethnic population live in London and they make up a quarter of the people living in the capital.

In recognition of London's diverse and multi-ethnic communities, the Alzheimer's Society (UK) has set up a black and minority ethnic community project based in the London regional office.

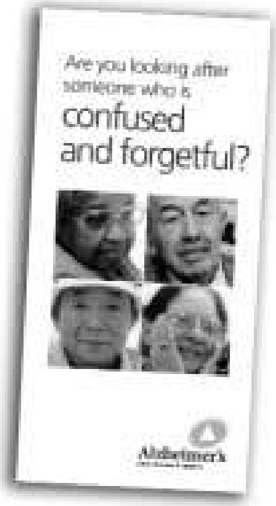
The project will assist black and minority ethnic organisations to recognise and understand dementia, and to develop and strengthen links within communities in London in order to raise awareness of Alzheimer's disease and other dementias.

Little is known of the experience of dementia and the needs of these communities. However, there are several black and minority ethnic older people community projects in London, set up to support carers. These provide a range of services, including respite care and support groups where carers can meet on a regular basis in an environment consistent with their cultural, language and religious needs.

These projects are often a lifeline for ethnic communities and are relied on for the provision of information on health, housing and benefits.

It is intended that this project will start working with black and minority ethnic elder community groups and organisations to increase their knowledge of dementia and develop services appropriate to their cultural language and religious needs.

If you would like to know more about the project or share information on similar projects in your region/country please contact Bolaji Bank Anthony, Black and Minority Ethnic Community Officer, Alzheimer's Society, London Regional Office, 45-46 Lower Marsh, London, SE1 7RG; tel: +44 (0)20 7620 3020; fax: +44 (0)20 7401 7352; email: bbankanthony@alzheimers.org.uk



One of a series of 14 leaflets in different languages produced by the Alzheimer's Society

The International Year of the Volunteer

'I always thought that life would not demand more than I could manage,' noted one caregiver but she continued, 'That was before I met Alzheimer's disease.'

Coping with Alzheimer's disease is often too much for any one person to manage. A volunteer can be that extra pair of hands that makes a huge difference in all dementia long term care, from in-home to residential care.

The Helping Hand, a dementia-specific day centre operated by the Alzheimer's Association (USA) chapter in Lexington, Kentucky, has utilized volunteers who have completed a 16-hour course of study, to give all the hands-on care since the programme opened in 1984. Volunteers, with diverse backgrounds of age, interest and culture, provide sensitive, loving and knowledgeable care. This individualised companionship helps to change normal anxious and frustrated feelings to safer, more secure and valued feelings. These volunteers, with the supervision of a director, have improved the quality of life for hundreds of people with memory loss and provided their caregivers with quality time.

What a person with Alzheimer's disease needs most of all is a good friend, a 'Best Friend'. Jane Owen, a volunteer in the Helping Hand for over 17 years says it best, 'Being a volunteer brings me as much joy as I bring to others. Most of my 'best friends' are participants in the Helping Hand.'


Volunteer Jane Owen (right) with Lucy King (left).

During this 'International Year of the Volunteer' give thought to recruiting and educating volunteers to 'stand beside you' in Alzheimer's care. Volunteers can help make a challenging situation more manageable.

Virginia Bell
Program Consultant, Alzheimer's Association, Lexington, Kentucky, USA

World Health Day 7 April 2001

'Stop Exclusion: Dare to Care', the theme for this year's World Health Day, was observed by several ADI members.

The Kolkata Chapter of the Alzheimer's and Related Disorders Society of India (ARDSI), in collaboration with Indian Medical Association, organised a seminar on mental health and a free health check-up camp. Discussions centred on the nature of dementia and the importance of care beyond medicine. The event was well attended by health care professionals, caregivers, people with dementia and the general public, and covered by the leading daily newspaper and local TV.


Venezuelan Health Minister, Dra Maria Urbaneja at the World Health Day conference in Caracas

The Fundación Alzheimer de Venezuela, in association with NGOs from the other mental disorders selected, hosted a conference attended by the Ministry of Health and the World Health Organization representative for Venezuela. The sessions concerning Alzheimer's disease featured support groups, treatments, the impact on the family and the work of the Fundación. The conference was well attended and received wide television, radio and newspaper coverage.

The Alzheimer's and Related Disorders Association of Thailand participated in an awareness raising event organised by the Mental Health Department in the Ministry of Public Health. The association spoke about Alzheimer's disease and distributed leaflets.

APEAD, the Alzheimer association in Peru, marked the day with a conference and the opportunity for people to attend a support group.

A new look at www.alz.co.uk

ADI has rewritten and restructured its website. Visitors will now easily find information on ADI, dementia, where to find help, and the global impact of dementia.

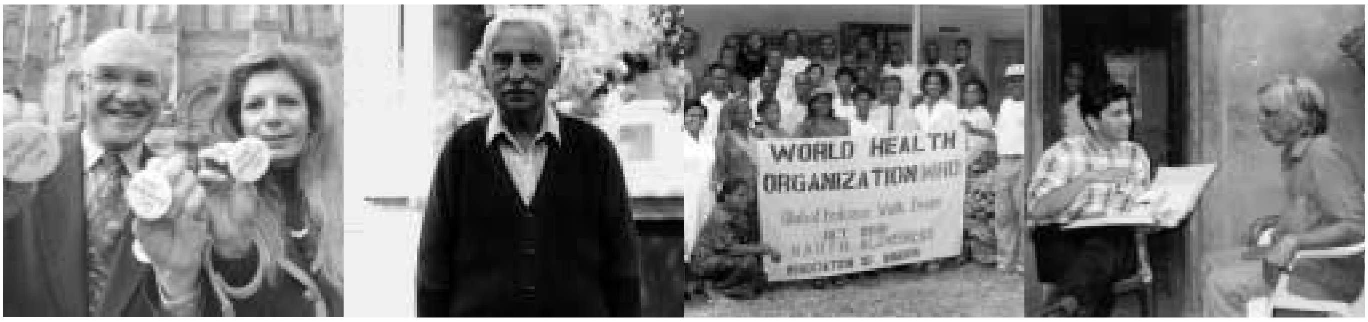
A new feature of the site is the information about Alzheimer's disease and other dementias. These pages include frequently asked questions, and information about the causes of dementia, treatments and help for caregivers. The section 'I have dementia' contains information for a person who has just received a diagnosis of dementia, and emphasizes that in the early stages there is much that can be done to help make life easier.

You may be surprised to learn that information about dementia is available on the Internet in a number of languages such as Vietnamese, Croatian, Bengali and Thai! Our alphabetic listing of other languages with links to appropriate sites makes accessing this information straightforward.

Questions centring on the global impact of dementia are an area of frequent request. The new site offers comprehensive information of the prevalence of dementia and the ongoing epidemiology work of the 10/66 Dementia Research Group and the World Health Organization.

Visitors will also find more information about ADI, our structure and activities, and will be able to download and print our publications. Finally, as with the previous site, you can look up contact details of the national Alzheimer association in your country.

The new website contains comprehensive information about ADI, dementia, where to find help, and the global impact of dementia



First International CJD Day 12 November 2002

12 November 2002 has been nominated as the first International Day for Creutzfeldt-Jakob Disease. The purpose of this day is to raise awareness about all forms of this rare disease, which has received worldwide media attention through links between variant CJD and BSE.

CJD is one of a rare group of fatal diseases which affect the brain through an agent known as a prion. It causes dementia and a range of neurological and psychiatric symptoms. These include unsteadiness and jerky movements and behavioural and communication difficulties. There are four forms of CJD: sporadic CJD; variant CJD; iatrogenic CJD; and familial CJD.

Europe is currently very worried about BSE and the potential development of variant CJD. Improved surveillance of CJD is being carried out in Europe and in many other countries throughout the world. The World Health Organization has recently published Infection Control Guidelines for Transmissible Spongiform Encephalopathies.

The CJD Support Network, the only registered UK charity supporting people affected by all forms of CJD, invites organisations throughout the world to join them. It is arranging events and creating opportunities to raise awareness and understanding of this disease.

These events should enable clear information about the disease to be disseminated and allow people to make decisions and choices about their risk of being affected. They will also encourage governments and related organisations to consider what further steps they can make to support patients and carers and to minimise risk for others. The CJD Support Network is planning a special Memorial Service for people who have been affected, and a Parliamentary event or conference.

For more information contact Gillian Turner, CJD Support Network case co-ordinator, Birchwood, Heath Top, Ashley Heath, Market Drayton, Salop, TF9 4QR, UK
tel/fax +44 (0)1630 673993
email cjdnet@alzheimers.org.uk