Global Perspective
Alzheimer's Disease International
SPRING 1997
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A newsletter for Alzheimer's Disease International, The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.

IN THIS ISSUE

New drugs for Alzheimer's disease

A new drug, donepezil, (E2020 or aricept, trade name) has just been licensed for use in patients with Alzheimer's disease in the USA, and may be shortly approved in the UK. It is made available by two companies Eisai and Pfizer. Like the other drug (tacrine) already licensed in the USA for use in the disease, donepezil works by slowing the breakdown of acetylcholine in the brain. This chemical substance is important for the passage of messages between nerve cells, and is deficient in the brains of people with Alzheimer's disease. If its breakdown can be prevented or slowed, this could help people with Alzheimer's disease.

Rigorous drug trials have shown some patients given donepezil do not deteriorate as rapidly as those who have not received it. Their memory and general functioning remain preserved for longer. This effect may last several months, possibly even longer. However, there are a number of reasons why enthusiasm can only be moderate at this stage.

The drug is only helpful in a minority of people who take it. It is not possible to predict in advance who will benefit and who will not. It has only been shown in the clinical trials to be effective in people with Alzheimer's disease of mild to moderate severity. Patients who have advanced disease have not been shown to benefit. A minority of people who take the drug suffer side effects such as diarrhoea, nausea and disturbance of sleep. The drug is likely to be expensive and requires skilled monitoring by a doctor while it is being taken. Finally, it is not clear yet whether the drug prolongs life. Some people with Alzheimer's disease and their carers wouldn't wish to prolong the condition. Others would be pleased for a continuation of life even if its quality is much reduced.

Any organisation wishing to know more about the situation concerning the availability of these drugs in their own country should consult their medical advisors. Individuals should consult their doctors or their local Alzheimer's association or society.

A cautious welcome from ADI

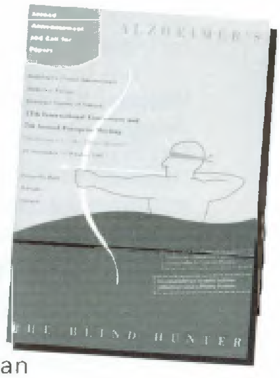
Professor Henry Brodaty, Chairman of ADI's Medical and Scientific Panel, counsels that *'while donepezil is a major advance in the treatment of Alzheimer's disease, it is not a cure. It will help* <u>*some*</u> *people* <u>*some*</u> *time, this might be stabilisation of the disease process rather than improvement. Others will not be able to tolerate the drug or not derive any benefit. It is not possible yet to predict who will respond. ADI is excited about the development of new and better drugs for the treatment of Alzheimer's disease. Drug treatments complement counselling and advice to people with Alzheimer's disease and good care by families'*

International Conference

Alzheimer's – The Blind Hunter

Helsinki, Finland

September 29 to October 1 1997



The Alzheimer's Disease International 13th International Conference and 7th Annual European Meeting of Alzheimer's Disease is this year being hosted by the Alzheimer Society of Finland in Helsinki. The main theme of the conference, *The Blind Hunter*, expresses that Alzheimer's disease can involve every one of us: those who will be stricken with dementia as well as their family members. Also, a growing number of professionals will face people with memory disturbances and dementia.

About 1200 participants from all over the world are expected to attend the meeting. We hope that we will be able to build up a unique and stimulating atmosphere for fruitful discussions and networking as well as spreading knowledge of the latest developments.

We hope to see you all in Helsinki next autumn.

Timo Erkinjuntti, Chairman of the Alzheimer Society of Finland, and Varpu Kettunen, Executive Director

ANNOUNCEMENTS

CONFERENCES

1997

Alzheimer's Disease International 13th International Conference
September 29 – October 1 1997
Finlandia Hall, Helsinki, Finland
Main themes: advances in the care of dementia, new perspectives on services development, innovative approaches to support family carers, human and legal rights of those with dementia. Contact: Alzheimer Society of Finland
Tel: + 358 9 6226 2013
Fax: + 358 9 6226 2020

Widening Horizons in Dementia Care
May 15–18 1997
Blackheath, London
An international conference with special focus on the use of reminiscence and life review in health care. Contact: Age Exchange Reminiscence Centre,
11 Blackheath Village,
London SE3 9LA
Tel: +44 (0) 181 318 9105
Fax: +44 (0) 181 318 0060

1st Bologna International Meeting on Cognitive and Affective Disorders in the Elderly
June 19–21 1997, Bolgona, Italy
Contact: Organising Secretariat
Tel: +39 521 290191
Fax: +39 521 291314
Email: medicina.viva@rsadvnet.it

8th Congress of the International Psychogeriatric Association (IPA)
August 17–22 1997
Jerusalem, Israel
Aging in a World of Change
Contact: IPA. Tel: +1 847 3754719
Fax: +1 847 375477
Email: orgIPAhq@aol.com

The Regional Meeting of World Psychiatric Association
Dementia, Schizophrenia, Depression
October 7–10 1997. Beijing, China
Tel: +86 10 62091953
Fax: +86 10 62027314

1997 World Congress of the World Federation for Mental Health
Cornerstones for Mental Health
July 6–11 1997
Lahti and Helsinki, Finland
Tel: +358 9 615 516
Fax: +358 0 692 4065

US Alzheimer's Association 9th Annual Public Policy Forum
April 26–29 1997
Washington DC, USA
Tel: +1 202 393 7737
Email: annetha.hall@alz.org

XIX Congreso Latinomericano de Psiquiataria
XIII Congreso Argentino de Psiquiataria de APSA
Identidad en la Globalizacion
April 9–13 1997
Mar del Plata, Argentina
Tel/Fax: +541 393 3059
Email: xixapal@apsa.fmed.uba.ar

1998

Alzheimer's Disease International 14th International Conference
September 25–27 1998
Cochin, India
Dementia the Global Challenge
Contact: Conference Secretariat
Tel: +91 488 522939
Fax: +91 488 522347

Fifth International Geneva/ Springfield Symposium on Advances in Alzheimer Therapy
April 15–18 1998
Geneva, Switzerland
Tel: +1 217 782 7711
Fax: +1 217 785 4413
Email: ogden@wpsmtp.siumed.edu

First International Conference on Family Care
Caring for Carers
May 14–15 1998
London, UK
Contact: Carer's National Association
Tel: +44 171 490 8818
Email:
icc98@carersuk.demon.co.uk

Global Perspective

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WORLD ALZHEIMER'S DAY – SEPTEMBER 21

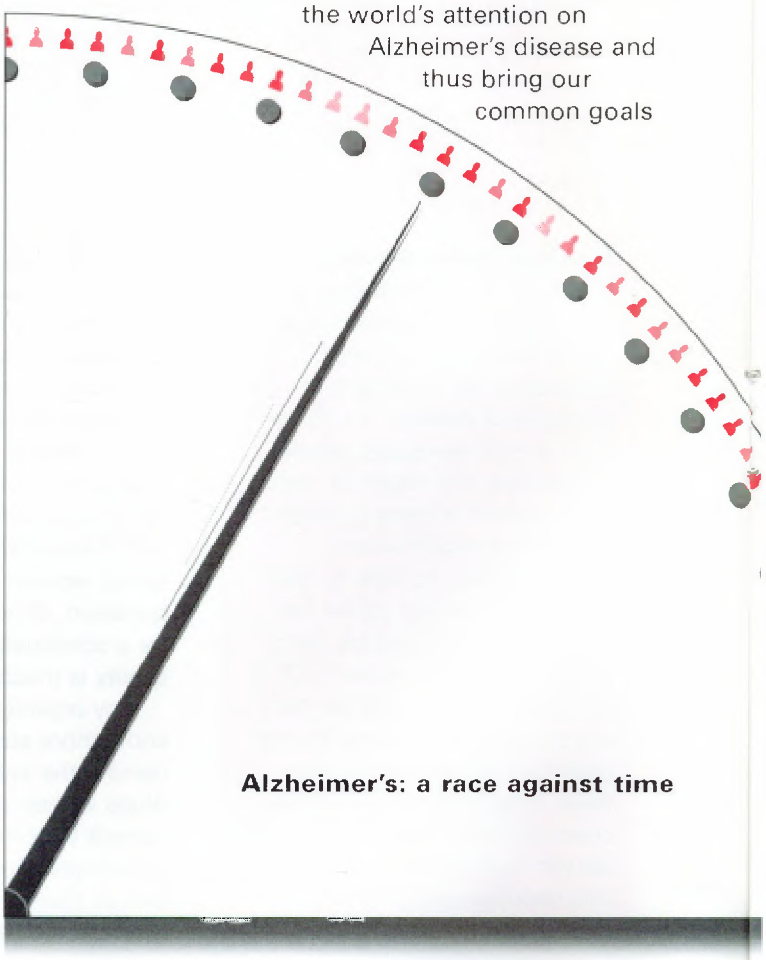
Alzheimer's: a race against time...

Harry Crielaars, Executive Director of Alzheimer Nederland

How many people are there in the world with dementia? Tens of millions perhaps, or even more? How many people will develop dementia? Do you know? Probably not, because the information about this is scattered all over the world. ADI is keen to raise awareness about this issue and is organising an exciting international campaign *Alzheimer's: race against time* to be launched on World Alzheimer's Day (WAD), September 21 1997.

WAD was first celebrated on September 21 1994. From that day, there have been many activities organised by ADI members to mark this annual event and raise awareness that Alzheimer's disease is a growing global challenge. More needs to be done.

ADI feels that launching a global theme for WAD 1997 and coordinating member countries' national activities within a large media event will focus the world's attention on Alzheimer's disease and thus bring our common goals



Alzheimer's: a race against time

more rapidly to fulfilment.
One of the most important parts of the campaign will be a charter, translated into several languages, which will state how many people there are in the world with dementia and that the number is growing by the minute. We are hoping that the charter will be in the form of a special newspaper which can easily be sent all over the world. We plan to create three chains of member countries and have the charter faxed along each chain from one member to the next.

Three suggested routes are:

- New Zealand → Japan → Germany → Poland → Finland → Sweden → Denmark → Scotland → Canada → USA
- Australia → South Africa → Spain → Luxembourg → Belgium → Brasil → Argentina → Chile → Mexico → USA
- India → Israel → Romania → Italy → Austria → Switzerland → Netherlands → UK → Ireland → USA

ADI member countries will be asked to organise a press conference or other public event and invite a national VIP, eg a politician or actor, to sign the charter. The idea is that once the charter has been signed it will then be faxed to the next country in the chain, signed and faxed to the next. All three chains will end in the US where a global press conference will be held. An internationally known person will then read out the charter.

For the event to be successful we will need the participation and support of as many member countries as possible. If you have any comments or suggestions about the campaign please contact me:

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The Netherlands.
Tel: +31 30 659 6285.
Fax: +31 30 659 6283.
Email:
alzned@worldaccess.nl

Living with Alzheimer's

By Hadassah Khan, Caregiver, South Africa

I never thought that I had a raging temper, or was highly volatile. Living with my husband for some years before I hospitalised him brought out areas in my nature I didn't think were possible. I resorted to throwing slippers at this man, shouting at him and sometimes wanting to throttle him.

Of course, after these outbursts, I was truly contrite – until the next time I felt myself losing total control. I know of course that he was not responsible for the things he did – such as arguing about getting into the bath and trying to sit in the bath, the wrong way – but it didn't help to reason with him.

He was beyond reason. He broke a drawer and steadfastly refused to acknowledge this. Of course he had no memory of this and similar incidents. He would answer the telephone and not give me messages. He had no idea how to put on his clothes, and instead of undoing buttons on his shirt would simply rip the shirt off, scattering buttons like confetti.

After I was persuaded by my family to institutionalise him I suffered a mild breakdown. My immune system went hay-wire. I was really ill, couldn't eat, lost weight and hair, and my face wrinkled! But slowly I started eating and felt reasonable – not happy, this can never be, but at least everyday happenings do interest me.

A good deal of life is sharing, and with a partner who has dementia this is absolutely impossible. It is a very lonely life being a carer.

When a partner dies there is a period of mourning and after an unspecified time, the living member of the marriage can get on with life. But in the case of being a carer, the sick person is always in the background and cannot be forgotten.

No matter how one travels, the thought of the patient is always there in the background. President Reagan has said that he feels that Alzheimer's disease is an ongoing funeral. I call it a living death.

There are many emotions from which one suffers. The first important one is guilt. Because of the nature of the illness, sufferers are not easy to handle. They may be aggressive and uncooperative, and the carer has to cope. At the beginning of the illness it is not easy to 'tag' the illness. You just think it's old age. But then when it does penetrate, you feel guilty at remonstrating, being angry and even being horrible.

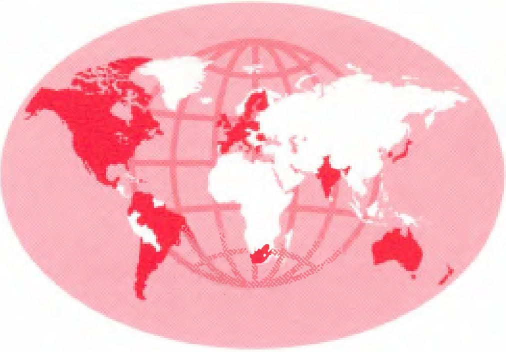
After the guilt, you then feel pity, dreadful pity at the indignity of your husband or wife. And, of course, remorse for not being able to deal with the sufferer's mood swings.

The carer has to be positive about the future. And the carer's life has to continue, albeit alone. You have to survive. You learn to eat alone – not easy.

A difficult thing to accept is the reaction of friends, and their behaviour towards the carer. Usually people don't know how to react, so they don't ask about the sufferer. I think out of embarrassment. And this just hurts. The sufferer is not dead. Just mentally not on this planet. But the carer is very much here and needs not pity, just empathy.

My first reaction to friends who wished to visit my husband was to say 'no please' because one is protective and embarrassed at the change they will find. It is not pleasant seeing a once robust, intelligent person talking nonsense and resorting to the first ages of man, written about so succinctly by Shakespeare.

To see a person after 47 years of marriage diminishing slowly in front of you is not easy.



Members' Forum

HONG KONG

The pearl of the Orient, by Dr C S Yu, Chairman HKADABFA

There are over 60,000 people with dementia in Hong Kong. The Hong Kong Alzheimer's disease and Brain Failure Association was officially formed on September 1 1995 with a foundation fund of HK$200,000. This followed a fund raising film show featuring a film about dementia, *Summer Snow*, which has won awards both in Hong Kong and abroad.

The executive is made up of carers and professionals. Our draft constitution has the following objectives:

- to advocate improvement in services and resources for people with dementia, their families and carers
- to promote knowledge about dementia and the caring skills required
- to increase public awareness of the disease and acceptance of those with Alzheimer's disease
- to provide sponsorship for local research.

Our association is very honoured to have Mrs Lavender Patten, the wife of the governor as our patron and many celebrities to be honorary advisers. Many professionals have agreed to be honorary members and promote the image and activities of the association. We have 200 members, many of whom are for life.

We run the organisation with volunteers.We have celebrated the last two World Alzheimer's Days with a carnival, an exhibition, a territory wide quiz and a variety show. Local fund raising events have also helped to raise awareness.

We hold regular support group meetings in the Community Rehabilitation Network and St James Settlement. An education programme features public talks, exhibitions, seminars, talks and training workshops for professionals. We also organise social events such as picnics for members and their carers. We provide home visits to members, a telephone hot line, a library/resource centre. We have good links with the mass media. We have published a booklet on dementia in English and Cantonese and have produced some educational leaflets. We have also translated some American videos about dementia into Cantonese. We launched our first seasonal bulletin in January 1997 and hope to produce this regularly.

We are running a strategic workshop in April to plan for the future of our association.

Our main problem is the lack of employed executive staff to man the increasing workload. We look forward to more collaboration with sister areas on running activities for those with dementia and their carers.

ABOVE: ***The foundation meeting of the Hong Kong Association.*** **RIGHT:** ***A group of volunteers on an Alzheimer's disease education programme***

VENEZUELA

Venezuela – a country with an area of 912,050 km^2 with just over 20 million inhabitants and an estimated 126,000 dementia sufferers of which approximately 63,000 have Alzheimer's disease.

Fundacion Alzheimer de Venezuela (FAV) was established in 1989 and became a full member of ADI in 1996. The Foundation has its main offices in the capital, Caracas, and four chapters with seven support groups.

FAV's main aims are:

- to give orientation, support and training to the family caregivers of patients with AD and other dementias
- to stimulate research and teaching programmes
- to inform and educate lay and professional people
- to promote pilot centres for diagnosis and care for the training of specialised professionals.

AUSTRIA

A report from Alzheimer Angehorige Austria

There are about 80,000 people with Alzheimer's disease in Austria. Our self-help group in Vienna is now seven years old and has 800 members. Invited speakers are part of our monthly meetings. The minutes of these meetings are sent to all members. In addition we have a small discussion group for in-depth discussion of continuing problems. Many of our lectures are given for listeners interested in the social organisation of the city of Vienna. Recently we set up a volunteer visiting service (sitting service) which has attracted many volunteers. For some time, we have participated in a Forum, along with interested physicians and representatives from pharmaceutical firms, where we try to advance certain important central subjects. These forums are useful in helping us obtain public attention and solutions for some of the problems confronting the group. Last year, the Forum put together the Alzheimer book *Leben mit VergeBlichkeit* (Living with Forgetfulness) which examined the illness from different viewpoints. It answers questions, gives tips, and lists contact addresses of social and medical agencies and institutions useful for carers. The book is put together with humour, is readable and gives a good overview of problems faced by those concerned with Alzheimer's disease. The book has been a real help to its readers and has been well received.

There are self help groups in all of the Austrian Provinces with whom we cooperate. We are also in contact with other groups in our region – Hungary, the Czech Republic. Slovakia, Slovenia and Romania. We support initiatives and plan to remain in continuing contact with them.

ITALY

Federazione Alzheimer Italia

The tragedy of Alzheimer's disease needs no letter of introduction. An estimated half million Italians are affected by this form of dementia. As is the case elsewhere, the immediate family acts as the core 'carer' force. Alzheimer Italia, headquartered in Milan, was established in 1993. In just 3 years, they have opened 25 chapters nationwide.

The immediate goals of the Italian organisation include:

- to provide information, guidance and advice that callers need about the disease
- to press for changes in national legislation on behalf of Alzheimer patients
- to provide legal counsel to families of Alzheimer patients
- to process the opening of day-care centres.

And much more!

CHILE

Corporación Alzheimer de Chile

by Beatriz Rose, volunteer, Alzheimer's Disease International

During a recent visit to Chile, I had the opportunity to visit the Corporación Alzheimer de Chile and meet some of the officers and volunteers.

The Chilean organisation was founded five years ago and has some 500 members, mainly in Santiago. Their present structure consists of a president, vice-president, secretary and a group of directors in charge of four committees – MSAC, comite psico social, family members and finance.

Like most third world countries, the Corporación often struggles to make ends meet financially. Yet, despite the difficulties, during 1996 with the help of many dedicated volunteers, most of them caregivers, they have maintained a 24 hour help line which gives information, support and advice seven days per week. They have also continued to operate a follow-up system for all callers and to staff some hospitals during geriatric clinics, to offer instant support to relatives following a diagnosis.

To this team of volunteers is added a group of professionals – doctors, psychologists, nurses and occupational therapists, all giving their time free. During the course of the year, apart form weekly seminars, which are a mixture of self support group and training for carers, the comite psico-social has managed to run one basic and two advanced training courses aimed at professional caregivers. The courses were well attended and popular. Similar events are planned for this year.

During my holidays, I also had the opportunity to speak to many lay people in Chile and when talking about Alzheimer's disease, most of them referred to programmes and advertising they had seen on Chilean TV, organised by the Corporación. It was apparent to me that this organisation has managed to reach the general public and raise awareness.

The Corporación has other ambitious plans for 1997, some of them have already have been put into practice, such as a group of psychologists and counsellors who are all trained and are at present writing their theses have been recruited by the Corporación to provide free help. Apart from fund raising events and potentially the publication of a newsletter, they are also intending to increase their presence in Chile by supporting the various groups which are beginning to contact the Corporación and encourage the formation of branches throughout the country. Given the geography of this thin and long country and the concentration of population in major cities, this is not an easy task.

Beatriz Rose (second from right) with Wilma de Rock, Julietta Montebruno, Eugenia Humeres and other members of Corporación Alzheimer de Chile

SPOTLIGHT

Alzheimer Society of Finland

By Sirkkaliisa Heimonen and Paivi Voutilainen

The number of people with dementia is increasing as the Finnish population grows older. In Finland the estimate of the prevalence of moderate to severe dementia is 6.7% of individuals aged over 65 and 17% of those aged over 85. These prevalence figures mean that there are presently about 70,000 people with dementia in Finland, which will increase to over 100,000 in the next few decades. In order to ensure the appropriate care and support for those with dementia as well as for informal and formal caregivers, the local authorities are challenged to evaluate existing structure of services and to vision the future solutions. The development of an appropriate service model must be based on careful evaluation of the needs of those with dementia and those caring for them.

The Alzheimer Society of Finland – the host of the next ADI conference – was founded in 1988 and is the umbrella organisation for 33 chapters throughout Finland. Financial support comes from the Slot Machine Association. The society works for the benefit of people with memory disturbances and dementia and their families. Advancing the human, social as well as legal rights of people involved in caring for those with dementia is the main goal of the society. To improve the standard of knowledge regarding rights, the Alzheimer Society of Finland published *A demented patient's bill of rights* in 1995. At the moment the activities undertaken by the society are numerous, the five main sectors of activities being:

- advancing and supervising the rights of those with dementia and their families
- organising services to improve the quality of life for those with dementia and to support their families e.g. through the dementia counselling services as well as adaptation training
- training professionals in order to improve the quality of care given to those with dementia
- influencing the decision making processes in order to develop the services for those with dementia in Finland.

Office staff

There are nine employees (full or part time) in the office at the moment:

- Executive Director: Varpu Kettunen
- Director of Education and Services: Sirkkaliisa Heimonen who organises the dementia counselling service as well as training for informal and formal caregivers
- Director of Development Unit: Paivi Voutilainen, who conducts different development programmes eg programme to advance dementia support services, music therapy programme as well as the cognitive rehabilitation programme for those in respite care
- Dementia Counsellor: Pirkko Telaranta
- Conference Manager: Tarja Tapaninen
- Office clerks

Leena's Home

Leena's Home was founded by the Alzheimer Society of Finland in 1989.

It is a special care unit for dementia clients. There are two wards and 20 beds available, 10 beds in each unit.

Leena's Home offers mainly respite care and is the first of its kind in Finland and therefore provides valuable data for research and development of the care of people suffering from Alzheimer's or related diseases.

Surroundings are home-like. Leena's home is located in the heart of Helsinki. The physical environment is based on the special needs of dementia patients. Meals are prepared in the home's own kitchen.

Clients in respite care are living at their own homes in between. They usually stay between two and four weeks. At one time there are 10 clients, five in respite and five in long term care. Severity of dementia

Nursing staff with a client at Leena's Home

is mostly either moderate or severe.

Care is based on good medical, nursing and psycho-social assessment. The goal is to support the quality of life and functional capacity. Supporting family caregivers is also an important aim to achieve. *The Alzheimer's Disease Bill of Rights* (by Virginia Bell & David Troxel, Alzheimer's Association USA) forms the ideological basis of care in Leenankoti. Primary nursing care modality is carried out.

Staff includes registered nurses, licenced practical nurses and trained home care workers. Two or three nurses in the morning and two in the evening create the daily routine together with clients according to their needs. The staff are specially trained to care for those with dementia. The doctor visits wards once a week and whenever needed.

The family caregiver has the opportunity for rest during respite care. The caregiver has a chance to discuss with staff members any problems with domestic care, to get advice and decrease the feeling of burden. The carer is also encouraged to ask for help and support from Leena's home during the period of home care.

All clients in respite care have been followed up. Age, sex, diagnosis, severity of dementia, physical functions and cognitive capacity are recorded. The rehabilitation method is the therapeutic community. The personnel are carefully selected and trained for both nursing care of those with dementia and working in a therapeutic community. The personnel are encouraged to analyse the feelings and human needs of each client. Observations and the individual life span of a client form the basis of the so called therapeutic approach.

The Helsinki conference

The biggest effort and challenge of the forthcoming months will be Alzheimer's Disease International 13th International Conference and 7th Annual European Meeting of Alzheimer's Disease which this year is being hosted by the Alzheimer Society of Finland in Helsinki (see page 1).

Early and presymptomatic diagnosis of Alzheimer's disease

BY DR ALEXANDER KURZ,
PROFESSOR OF PSYCHIATRY, TECHNISE UNIVERSITAET MUENCHEN, GERMANY

As more medications become available which have the potential to slow down the course of Alzheimer's disease and as preventive therapies are under development an early or even presymptomatic diagnosis is increasingly needed.

New discoveries

Two major scientific discoveries have provided a basis for such diagnostic improvements. First, rare forms of the disease which run in families and have an early onset are caused by errors in the genetic information carried on chromosomes 1,14 and 21. Second, death of nerve cells and disruption of nerve cell connections occur many years before the typical symptoms become apparent.

Presymptomatic testing

A presymptomatic diagnosis of Alzheimer's disease can be established by screening for genetic defects in unaffected relatives of patients who suffer from heritable forms of the disease. In these exceptional cases genetic testing must be accompanied by appropriate counselling procedures which include pedigree analysis, clinical assessment, pre-test counselling and follow up. Unlike the genetic errors on chromosomes 1,14 and 21, apolipoprotein E gene on chromosome 19 does not predict that an individual will acquire Alzheimer's disease but increases the individual's disease risk. Determination of the apolipoprotein E genotype should not be used for presymptomatic testing. In certain situations, however, it can make the clinical diagnosis of Alzheimer's disease more certain.

Early stage testing

Whereas presymptomatic testing will be confined to the members of very few families, a much greater number of individuals may benefit from the early recognition of Alzheimer's disease at a stage where only minimal symptoms are present. Several laboratory and technical approaches have been evaluated all of which are aimed at demonstrating the damage that has occurred to nerve cells. One approach is to screen for a small protein called tau in the cerebrospinal fluid, Normally, tau is only found within nerve cells. Upon dissolution of the nerve cell however tau is released into the extracellular space and into the cerebrospinal fluid. Tau concentrations are significantly elevated in Alzheimer's patients with very mild symptoms and there is almost no overlap with age-matched healthy controls. This suggests that tau levels may already be increased in the pre-dementia stage of the disease. This approach may be complemented by measuring the concentration of a protein referred to as beta amyloid. In Alzheimer's disease an abnormally long variant of this protein is preferentially produced which has a strong tendency to accumulate into amyloid deposits. This is probably the reason why its concentration in the cerebrospinal fluid is lower in Alzheimer's patients than in controls.

Brain scans

When a substantial number of nerve cells have undergone degeneration the brain tissues show atrophic changes. Shrinkage is first observed in the hippocampus. This part of the brain is situated in the medial temporal lobe and is most vulnerable to the disease process. Computed x-ray tomography and magnetic resonance imaging have demonstrated atrophic changes of the hippocampus in Alzheimer's patients with very mild dementia. Finally brain areas which are affected by the disease process exhibit a lower metabolic activity than regions which are spared. Positron emission tomography can demonstrate the typical pattern of metabolic hypoactivity over the temporal lobe in 60-80% of Alzheimer's patients with very mild dementia.

BOOK REVIEW

La Enfermedad de Alzheimer: la información como base para la prevención (Alzheimer's Disease: prevention through information)

By Elena F.L. Ochoa, Institute of Psychiatry, University of London

Summary: Alzheimer's disease is a condition which is all too common nowadays and unfortunately increasingly so. Information and education about dementia and Alzheimer's disease is considered the first step to achieve prevention as well as to improve the quality of life of those suffering from dementia and their families. The book 'Alzheimer's Disease' has proved a valuable tool for families with an Alzheimer's disease member, for clinical psychologists and psychiatrists and as well as for other health care professionals who work with those suffering from Alzheimer's disease.

La guía práctica 'La Enfermedad de Alzheimer' proporciona información sobre la demencia tipo Alzheimer a diversos espectros de lectores. En primer lugar, 'La Enfermedad de Alzheimer' está dirigida a las personas diagnosticadas con EA y que se encuentran en la primera fase de la enfermedad; en sugundo lugar, se dirige a las familias y a los cuidadores de las personas afectadas por la EA; en tercer lugar, a los estudiantes de medicina y de ciencias de las conducta; en cuarto lugar, a profesionales de la salud que trabajan con una población de edad superior a los sesenta años, esten estos profesionales especializados o no en cuadros de demencia y, en concreto, en la EA; y en quinto lugar, se dirige a las personas interesadas en conocer cuáles son las dimensiones personales y sociales seriamente distorsionadas por la EA.

La estructura de esta guía práctica se ha planifcado para su servicio en la labor de prevención. El diseño y formato permite una doble lectura: preguntas y respuestas en los laterales de cada página, pequeños resumenes y recopilaciones de los datos más importantes a procesar, llamadas de atención y señalizaciones de información esencial para el afectado o su familia. La redacción sencilla y la evitación de términos técnicos, permite obtener y memorizar datos sin excesivo esfuerzo.

Las guias que hemos elaborado en nuestro equipo y, en concreto esta sobre la 'Enfermedad de Alzheimer', ha contado con la colaboración de AFAL (Asociación de Familiares de Alzheimer de la Comunidad de Madrid) y ha tenido como punto de referencia la experiencia directa con los familiares y cuidadores.

THEATRE REVIEW

Change of Mind

A play by Peter Spafford

At the 1996 12th International Conference of Alzheimer's Disease International (ADI) in Jerusalem I saw the performance *Change of Mind*. My own story is similar to the one performed in the play.

When the play ended, the audience was invited to express their opinions to the author. I felt too emotionally strung up to say more than 'thank you'.

But this play was too powerful to let it pass with just a 'thank you'.

The writer's thorough research enabled him to present us with an absolutely convincing scenario, with all the weird behaviours and the reactions to them: garden bulbs in the cooking pot, a shopping basket full of tins of baked beans, an upside down gardening fork, a wonderful 'scene' at the Day Centre with too much stimuli – and the way Carol played down Doug's attempt to throttle her.

Photo: Lizzie Coombes

Without overdoing it, or trying to crowd too many different behaviours into one character, the play created a 'real' Alzheimer patient and a 'real' network of relationships between the family members. The minimal set allowed me to fill out the stage with my own furniture. The one solitary arm-chair that Doug always sat it, in the same pose, became for me, the armchair that my husband sat in.

This was a first rate performance of a first rate play. The visual impact of allowing the audience to enter the home of a family and watch these four people go through the agonising stages of Alzheimer's disease, is a more powerful educational medium than any number of books. This play will help a great number of people to understand what living with Alzheimer's disease means. I hope it has the opportunity to be seen by many, many, people.

Miriam Webber, Israel

Change of Mind *is available for international bookings from September to December this year. For further information and additional copies of the enclosed leaflet, please contact Sara Robinson at: mind the ...gap, 29 Queens Road Bradford BD8 7BS.*

Tel: +44 (0) 1274 544683

Global Perspective

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Send us your comments

If you have any comments or suggestions about the newsletter, or would like to submit an article – we are particularly keen to hear from carers around the world – please contact the Secretariat.

Put you requests for help in Members' Forum

Member countries requiring help or information are asked to put their requests in writing for inclusion in the next edition of Global Perspective. We would like to start a help column where these requests can be featured, inviting our readers worldwide to respond.