

Global & Alzheimer's Disease International Perspective

SUMMER 1996

VOLUME 6 NUMBER 3

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

Alzheimer's birthplace becomes museum and conference centre

On 19th December 1996, the beautiful German town of Marktbreit was host to a number of events marking the 80th anniversary of the death of Dr Alois Alzheimer. Central to these was the opening of the house where Dr Alzheimer was born and lived, as a museum and conference centre. Dr Nori Graham and Robert Gomez, representing ADI, and Dr Henk ter Haar, representing AE, were invited to the opening by Eli Lilly and Company.

Lilly, one of the world's leading pharmaceutical manufacturers in the research and production of medication for the treatment of psychiatric and neurological disease, acquired the house in the summer of 1995 and has now restored it. A small museum room has been decorated according to the style of the mid 18th century. With this, the owners want to recall the life-work of Alois Alzheimer and to promote the scientific and social work in the spirit of the famous psychiatrist. Within the scope of the newly founded society *Lilly ZNS Forum im Alzheimer-Haus*, the conference room on the upper floor of the building will serve as a meeting place for scientists and therapists, as well as the patients and their relatives. The aim of the society is to advance the contact and interchange between the representatives of these groups. In this, the cooperation will not be limited to Alzheimer's disease alone, but focus on the entire field of psychiatric and neurological diseases. 'In the long run, we do not only want

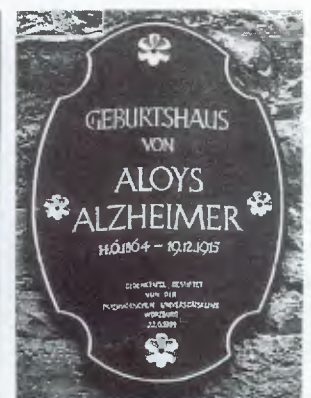
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Alois Alzheimer and the house in Marktbreit, Germany, where he was born



The new conference room



The plaque on the wall outside the house

CLINICAL TREATMENTS

Drug treatments for Alzheimer's disease

Scores of drugs are in various stages of development for the treatment of Alzheimer's Disease (AD). Most aim to enhance or replace neurotransmitters adversely affected by the disease process. Many of these have reached clinical trial stage and one, tacrine, has been approved in some countries for the treatment of mild to moderate AD.

The most frequent pharmaceutical strategy being employed is to enhance levels of acetylcholine in the brain. Most neurotransmitters, which are chemicals that carry messages from one nerve cell to another nerve cell, are markedly decreased in AD. Acetylcholine (Ach), the major neurotransmitter for memory, is the most severely affected of these chemicals. Most of the drugs now being studied for the treatment of AD aim to enhance levels or the action of Ach. Tacrine, melameline, galantamine, E2020, physostigmine and acetyl-L-carnitine are some examples of these.

However, outcomes of drug trials published to date have not been compelling. One reason may be that AD encompasses a group of diseases and this heterogeneity may be obscuring sub-groups of potential responders. Thus, apolipoprotein E4 status may predict poor response to tacrine.

For many years attempts have been made to differentiate sub-groups of AD by clinical or demographic features. For example, patients with early onset AD may experience a more rapid and severe disease progression than late onset patients – and so may have more obvious benefit from pharmacological therapeutic strategies.

Currently a multi-centre trial is being designed to test the hypothesis the acetyl-L-carnitine can slow the progression of AD in early onset patients. This is the first study to examine the effects of drug in a specific aged-defined population. This study, organized by Sigma-Tau across 32 clinical sites in North America, will enrol patients between the age of 45 and 65 until July 1996 and will follow them up for one year. People interested in learning more about this study may contact the Alzheimer's Association in the US +312 335 5731 or the Alzheimer's Society of Canada +416 925 3552.

Global Perspective

The views stated in Global Perspective are personal and not necessarily reflect the views of ADI

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ANNOUNCEMENTS

CONFERENCES

Alzheimer's Association of Australia - 6th Annual Conference

2 - 5 June, 1996
Hand it to the Carers
Hobart, Tasmania, Australia
Tel: +61 02 341424
Fax: +61 02 344464

B C Association of Community Care Annual Conference

3 - 5 June, 1996
Community Care - Focusing the Dialogue
Delta Pacific Resort and Conference Centre
Information: Jackie O'Brien,
Suite 101, 1700 West 75th Avenue, Vancouver, BC, V6P 6G2, Canada
Tel: (604) 263 1464
Fax: (604) 263 1458

Collegium Internationale Neuro-Psychopharmacologicum Conference - Melbourne

XX Congress
23-27 June, 1996
Information: Secretariat,
ICMS Pty Ltd, 84
Queensbridge St, South Melbourne, Victoria, Australia 3205
Tel: +61 3 682 0244
Fax: + 61 3 682 0288

The Brain Event - New Frontiers in Alzheimer's Research

Friday 5 July 1996
Queen Elizabeth II Conference Centre,
London SW1, UK
Chaired by Jon Snow and Professor Dame June Lloyd DBE. Speakers to include Michael Ignatieff and Dr Zaven Khachaturian
Tel: 0171 306 0606
Fax: 0171 306 0808

AA Education Conference

14-17 July 1996
Shaping Alzheimer Care: Power of Change
Sheraton Hotel & Towers,
Chicago, IL, USA
Tel: 312/335 5790

Alzheimer's Disease and Related Disorders

24-29 July, 1996
Osaka, Japan
Information:
Organising Secretariat,
'Alzheimer 96', Congress Corporation, Sunbird Building, 1-12-9 Oyodonaka, Kita-Ku, Osaka, 531 Japan
Tel: +81 6 451 7157
Fax: +81 6 454 4711

ADI 12th International Conference

October 8-11, 1996
'... to give you a future and a hope.'
Jerusalem, Israel
Conference Secretariat:
PO Box 50006,
Tel Aviv 61500, Israel
Tel: +9723 514 0000/0014
Fax: +9723 517 5674/0077
See back page for details

PUBLICATIONS AND RESOURCES

Alzheimer's Disease - Starting a Self-help Group

This booklet offers help in starting a self-help group for people who care for people with Alzheimer's disease and other forms of dementia. Available in English and Spanish free from ADI Secretariat

How to set up an Alzheimer's Society

Aimed at helping those starting organisations and those in the early stages. Available in English and Spanish free from ADI Secretariat

International Forum on Early Dementia

Multidisciplinary Perspectives on the Early Stages of Alzheimer's Disease
Special subscription offer: 4 issues for \$33. Add \$1 for postage to Canada; \$5 for other countries.
1067 Filbert Street,
Suite 100, San Francisco, California 94133, USA



Frau Ilse Lieblein (seated), granddaughter of Dr Alzheimer, with Frau Maurer, wife of Professor Maurer, in the parlour of Alzheimer's house in Markbreit. Frau Maurer was responsible for the restoration of the house.

continued from front cover...

to inform each other and talk about the pure science itself,' said Professor Konrad Maurer, head of the Psychiatrische Klinik at the University of Frankfurt am Main and a member of the managing board of Lilly's CNS Forum. 'We also want to help the public better understand and accept the disease'.

Professor Maurer had already in 1989 developed the idea of transforming Alzheimer's birthplace into a place of recollection and communication. He fixed a commemorative tablet to the house during a congress on the occasion of Alzheimer's 125th anniversary. When the inhabitants of the house, a family named Brandmann, planned to sell it, they contacted

the professor. As Mrs Brandmann is a nurse working with neurological patients, it was of particular interest to her to commemorate Alois Alzheimer in this way. It remained 'only' to find someone willing to purchase the building. 'The only purchaser who came to mind was a company that sees itself as a partner fully committed to our idea and to visions for the next millennium. This is why I contacted Lilly.'

The idea met with a favourable response there. Eli Lilly and Company, Indianapolis, and its German subsidiary Lilly Deutschland GmbH, Bad Homburg, each decided to finance half the purchase of the house. 'We invited the recently founded Society to coordinate the use of the Alzheimer-Haus and we

The 'Lilly ZNS Forum im Alzheimer-Haus' Society

The Society's purposes are

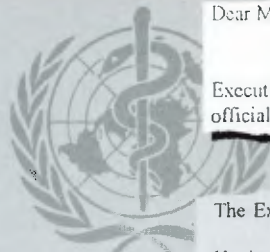
- To commemorate the psychiatrist Alois Alzheimer and his important work
- To promote the academic interchange between researchers of psychiatric, neurological and degenerative diseases
- To promote the collaboration between researchers, physicians, industry and patients as well as their caregivers concerned with psychiatric and neurological diseases
- To help to assist in the advancement of public understanding of neuropsychiatric diseases.

hope that the house will be used frequently and as soon as possible,' announced Robert N Postlethwait, President CNS-Business Unit of Eli Lilly. 'We will be very pleased, if representatives of different interest groups throughout the world come together in Markbreit to develop - inspired by Alois Alzheimer's thoughts - visions which allow all psychiatrically and neurologically ill people to live in a better way.'

ADI gains official relationship with WHO

The World Health Organisation Executive Board, at its 97th session in January 1996, has established official relations with Alzheimer's Disease International.

These are extracts from recent correspondence.



Dear Mr Gomez,

I have pleasure in informing you that at its ninety-seventh session in January 1996, the WHO Executive Board decided, by resolution EB97R.23, to admit Alzheimer's Disease International into official relations with the World Health Organization. A copy of the resolution is attached.

The Executive Board,

Having examined the report of its Standing Committee on Nongovernmental Organizations,'

DECIDES to establish official relations with the following nongovernmental organizations:

Thalassaemia International Federation
European Centre for Ecotoxicology and Toxicology of Chemicals
Alzheimer's Disease International, The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.
World Federation for Ultrasound in Medicine and Biology;

Alzheimer Canada's Wandering Registry

A helping hand for wanderers

Linda LeDuc, Director of Support Services and Education
and Debbie Krulicki, PR Coordinator
Alzheimer Society of Canada

One of the more challenging behaviours resulting from Alzheimer disease is wandering. Wandering is defined as 'extended periods or aimless and disoriented movement without full awareness of one's behaviour.'¹ This behaviour is the cause of much stress for caregivers, both family and health care staff. If done in a protected environment, wandering can be a meaningful activity. The behaviour becomes a concern when an individual has unrestricted access to the outside world. Problems can arise when a vulnerable person is no longer able to find his/her way home, does not recognize traffic signals or is unaware of unsafe weather conditions.

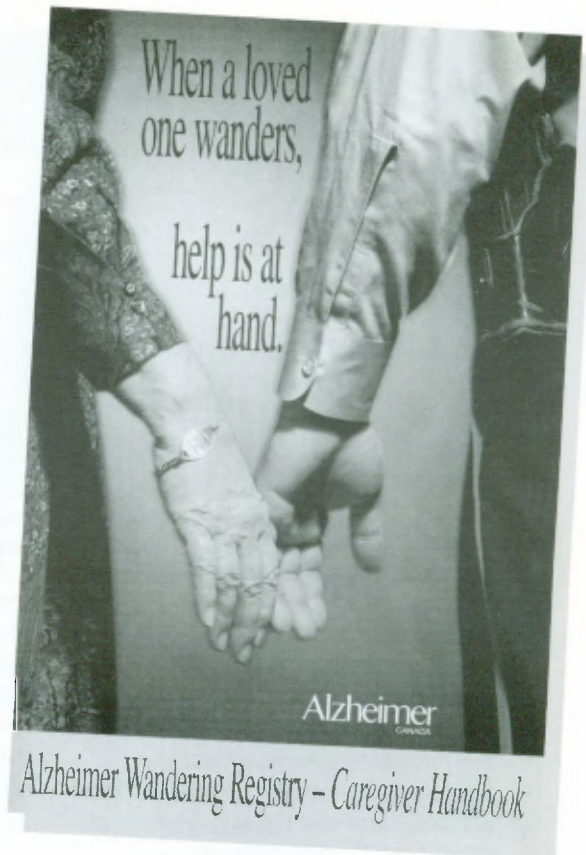
Precautions should be taken at home and in long-term care facilities to prevent wandering, but should those fail, it is necessary to have a program which will facilitate an individual's safe and speedy return home.

Wandering registries in Canada have been administered by local Alzheimer organizations since 1988 with the first one established in Metropolitan Toronto. In 1992, the Support Services & Education Committee of the Alzheimer Society of Canada identified wandering registries as a program area which needed to be explored from a national perspective. Provinces were struggling to develop registries, but nowhere had the information been consolidated or models evaluated for effectiveness. Given

that the Canadian Alzheimer organization consists of local, provincial and national levels, it was vital to explore a coordinated and effective registry model.

In December of 1992, the Royal Canadian Mounted Police (RCMP) approached the Alzheimer Society of Canada to discuss the development of a nation-wide Alzheimer Wandering Registry. This idea was based upon requests from regional detachments of the RCMP wanting to add a number of regional wandering registries onto the Canadian Police Information Centre (CPIC), the national database for policing agencies across the country. CPIC seemed to be the most likely home for a nation-wide registry and the Alzheimer Society of Canada, the most likely partner. Policing in Canada is provided by over 2,500 federal, provincial and municipal agencies which all have access to CPIC. The users include customs and railway police. The benefit of a nation-wide registry included the accessibility of information to police should an individual wander from the policing jurisdiction they live in to another.

The major components of the Alzheimer Wandering Registry include a database of individuals at risk of wandering, police and caregiver information and training and some forms of identification for the individual (bracelet, ID cards, clothing labels). Registration is voluntary. A person's identification provides police with the necessary information should they encounter an individual who is confused or



Alzheimer Canada have produced this clear and simple guide for carers

disoriented. The database has descriptive information about the registrants as well as a list of caregivers to contact should an individual be found. The registry also enhances the ability of the police to respond to a missing person's report. The information required for searching is already in the system, which helps to speed up the process once the report is received. Although the program is nation-wide in scope, all contact with families and local police forces is done by the provincial or local level of the Alzheimer organization best prepared to offer this service.

Alzheimer Canada sought out partners to assist in the realization of the program. The Canadian Medic Alert Foundation, a national non-profit organization with an international network, provides registrants with an ID bracelet that identify medical conditions in an emergency. The foundation has a 24-hour support line. The Block Parent Program of Canada Inc. is also part of the program. Present in 1200 communities and 276,000 homes, this national network provides reassur-

¹ Cohen, U et al, Holding on to Home, Johns Hopkins Press, Baltimore, 1991, p.69

Arrangements for our 12th ADI International Conference, hosted this year by the Alzheimer's Society of Israel, are well in hand and a good turnout of members is expected. It will be good to get together with friends from so many different parts of the world and to be able to exchange views and ideas about the various activities going on in our member country Alzheimer associations. Importantly we look forward to hearing the latest updates on drug studies, as the world increasingly strives to research the cause and cure of Alzheimer's disease.

In the meantime we in ADI continue to support the families and other carers of people suffering from this terrible disease, through our member associations spread over thirty six countries. By the end of this year we are hoping to have five new member countries and much work is being done to support the creation of Alzheimer's disease associations in many parts of the world. Some of our members are being very active in this field, bringing much needed help and advice to neighbouring countries. A good

Reflections from the Secretary General

example of this is the Alzheimer's and Related Disorders Association of South Africa which is now assisting members in Zimbabwe, Swaziland, Botswana and Namibia.

Some weeks ago I was invited to address the Annual General Meeting and Conference of the Alzheimer's Association of Puerto Rico where I witnessed at first hand the work they have been doing over the past few years in assisting neighbouring countries and stimulating the creation of Alzheimer's associations in the region. While the meeting was predominantly a national meeting, a number of countries had been invited to send representatives, and among those present were Guatemala, Colombia and The Dominican Republic. The latter two have applied to join ADI this year and Guatemala was admitted as a provisional member last year as many of our readers will know. This international cooperation was very prevalent in our conference in Buenos Aires last year and I



know this will also be the case this year in Jerusalem. International cooperation was also highlighted in Warsaw last April when it was agreed that the annual conferences of ADI and that of Alzheimer Europe, both of which were scheduled to take place in Europe in 1997, would now be held jointly in Helsinki, Finland.

Now, as our feet tread a path towards Israel, I hope that as many of you as possible will join us in Jerusalem next October to participate in what promises to be a most informative and enjoyable programme, in the knowledge that every step we take is bringing us that little bit closer to understanding what Alzheimer's disease is and how best to cope with it.

Robert A Gomez

ance to communities across the country by keeping an eye on the street for children in trouble. Their role has now expanded to watch for individuals who are wandering. Their large support network will enhance community awareness and provide registrants with an additional community resource.

Each individual wishing to register pays a one-time \$25 registration fee. Information about the individual is recorded including a physical description, medical problems, places likely to wander and caregiver contacts. This information is entered in to the CPIC and MedicAlert systems. The individual receives a MedicAlert bracelet, identification cards and the booklet *Alzheimer Wandering Registry: Caregiver Handbook* which provides information on wandering, tips for prevention and what to do in the event of wandering. The database

files are updated on an annual basis. Training is a large part of the registry program. Increasing awareness and understanding of Alzheimer disease and the registry within the police community is one goal of the project. To accomplish this, the *Alzheimer Wandering Registry: Police Handbook* was developed as well as a training session outline in a speakers kit. This kit also contains information for family caregiver education sessions. In order to increase awareness of the program, posters and brochures were developed for distribution in pharmacies, health care agencies and corporations across the country. Alzheimer Canada received news of funding in January of 1995 when Health Canada and Solicitor General Canada approved a two-year grant of \$399,000. In addition to the direct funding, Solicitor General Canada is providing the Registry with access to CPIC and the necessary com-

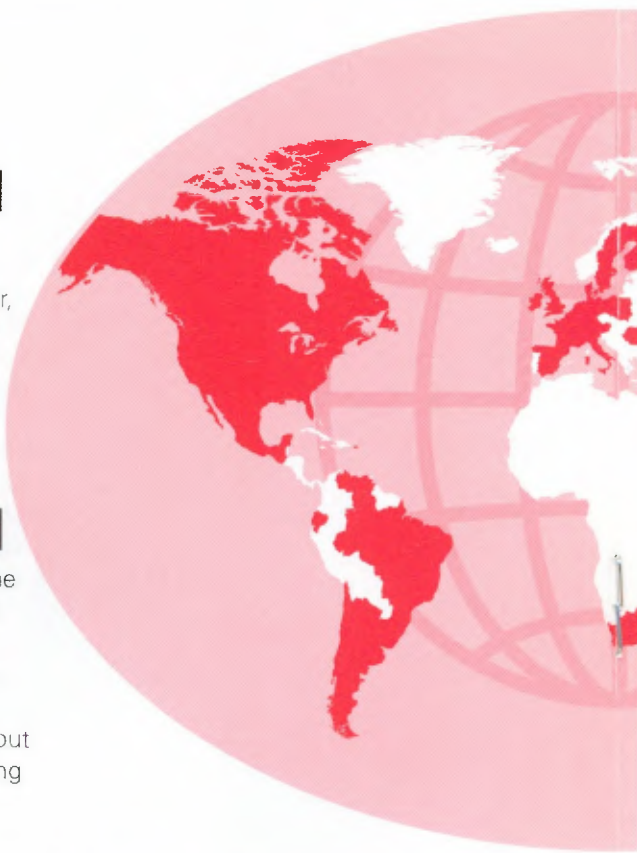
puter software to allow Alzheimer Canada to maintain the system. The first transfer of data occurred on September 1, 1995. As of December 31, 1,200 individuals were on the system.

The registry will not entirely prevent wandering nor will it prevent all tragic endings, but it does provide a community prepared to assist in the event of wandering and peace of mind for caregivers. As the program motto reads, 'When a Loved One Wanders, Help is at Hand.'

For more information about the program, please contact Linda LeDuc, Director, Support Services & Education at Alzheimer Canada, 1320 Yonge Street, Suite 201, Toronto, Ontario, M4T 1X2, Canada. Telephone (416) 925-3552 Fax (416) 925-1649 e-mail ac594@toronto.freenet.on.ca

Members' Forum

News from around the world



URUGUAY

A country with an area of almost 69 thousand square miles, just over 3 million inhabitants and an estimated 30 thousand Alzheimer sufferers.

AUDAS, (Asociacion Uruguaya de Alzheimer y Similares), was established in 1991 and became a full member of ADI in 1994. The association has its main offices in the Capital, Montevideo and support groups in three provinces with a total membership of 200 members.

Activities include free information and advice, training, self-help groups and a helpline. Much has been done in terms of publicity by AUDAS, via radio, TV, various open meetings in schools, community centres and a symposium. They have translated material and information into Spanish including 'Help for Caregivers' (a WHO-ADI publication) to make it available to carers in Uruguay. AUDAS has many future

plans such as starting a newsletter, day centre and a two-day seminar for carers and professionals to take place on 13th and 14th May this year. Neighbouring countries please note.

PUERTO RICO

The 13th Annual Conference of the Alzheimer's Association of Puerto Rico took place in Ponce, Puerto Rico on March 30th. The keynote speaker was Robert Gomez, ADI Secretary General, who spoke about the work that ADI is currently doing and its plans for the future. The meeting, which was very well attended, also included representatives from Alzheimer's Associations in Guatemala, Colombia and the Dominican Republic. The latter two have applied to join ADI this year.

ADI applauds the initiative of AAPR in giving their AGM an international flavour, which has helped to create a much better understanding of the work being carried out in those countries represented and has already resulted in a welcome interchange of ideas and practical help.

FINLAND

The Association in Finland has embarked on a project to set up a special centre for Alzheimer's sufferers with facilities for the care of 20 patients on two floors, the housing of the Alzheimer Society of Finland, rooms for dementia counselling and also for education purposes. An old industrial building will be renovated to house this centre in Helsinki. The project is partially funded by the 'Slot Machine Association of Sweden'.

A scheme has also been set up to raise funds by offering supporters the chance of acquiring 'gold nails' especially designed by the famous Finnish artist Timo Sarpaneva. The official opening will take place on 19 September 1996.

EGYPT

Contact has been made with two doctors working in the Middle East who have separately made tentative plans to establish a society in Egypt. The Secretary General has written to both in the hope that they may be able to combine their efforts. ADI will be actively encouraging and supporting them in the future.

KOREA

On 22nd February ADI received the visit of a team from the Korean Broadcasting Corporation who interviewed Nori Graham on the activities of ADI. This interview will be part of a special programme to be broadcast by the Korean television network later in the year.

JAPAN

A 24-hour help line was introduced by the Ministry of Health and Welfare in connection with the Nursing Home Services programme which started in April 1995. It is being introduced in 20 cities throughout Japan to lighten the burden of carers through the night. Helpers make home visits

USA

Special offer on a new publication:

Activity Programming for Persons with Dementia: A Sourcebook. A compilation of activity programming ideas for nursing homes, adult day centres and in-home care providers.

Free copies available to first ten orders received from ADI members, by kind courtesy of US Alzheimer's Association. Apply to ADI. Further copies at US\$20.00 (US\$16.00 for ADI members) direct from Alzheimer's Association, 919 Michigan Avenue Suite 1000, Chicago, IL 60611, USA, quoting AA/ADI Offer.



ECUADOR

A country with an estimated population of over 11 million inhabitants in an area of some 105 thousand square miles.

Fundacion Alzheimer de Ecuador, (FAE), was started by Sr Galo Andrade and has been a provisional member of ADI since 1994. FAE obtained legal status in Ecuador in 1995.

FAE's initial aims were:

- To promote basic research and understanding of AD, also possible treatment and prevention.
- To promote public awareness of the illness.
- To create a support network for relatives of AD patients.
- To promote improved legislation on matters affecting AD sufferers.

FAE has now three branches and provides several services, such as regular newsletters, training, self-help groups, and dental and medical services for AD sufferers.

FAE's main project for the future is to build a day centre for people with Alzheimer disease.

INDIA

ADI course on dementia

'This training course has been a most unique experience for us', said a number of the participants at the Alzheimer's Disease and Related Disorders Society of India.

Twenty participants from various provinces, religious backgrounds and walks of life attended a 14-day course in Cochin in the south of India. The course covered basic knowledge about the dementias, ways to care, how to set up a Day Care Centre and Nursing Home. The final component was a 'Train the Trainer' course so that India now has a number of excellent trainers. The trainers can set up and run support groups and day care centres. The participants further stated that their thinking had undergone a complete turn and they now saw people with dementia as having abilities and the staff would be able to give individual care. The commitment to caring and the responsibility the participants took for their learning was a most gratifying and humbling experience for the trainer, Mrs Francesca Jordan.

following a prepared schedule and the charges per visit range from free to 750 Yens (US\$ 6.60 approx).

The spread and success of this programme will depend on the manpower and budget available.

ALZHEIMER SCOTLAND - ACTION ON DEMENTIA

Daycare Services

Alzheimer Scotland - Action on Dementia runs over 30 separate daycentres throughout Scotland. These centres are designed to be models of good practice as well as provide much needed assistance to people with dementia and respite for their carers.

The largest daycentre is for 12 people, the majority have between five and eight places.

Most of the daycentres are located in premises belonging to other organisations such as churches and housing associations.

We normally provide daycare alongside services for carers such as advice and information, carer support groups and carer educa-

tion. We also try to provide home support services from the same base, but this is not always possible.

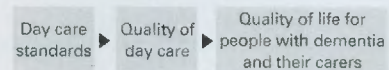
The direct costs of daycare services are almost entirely met by either the Government, local authorities or health boards. The indirect costs of regional management are partially funded from charitable income.

Daycentres are staffed by a combination of paid employees and volunteers - for example, an eight-place day centre will normally have a daycare manager, care assistant and at least two volunteer care workers.

A great deal of importance is attached to individual care programmes for daycentre users, training for staff and volunteers,

planned activity programmes and evaluation.

Daycare is designed around the following approach to quality:



Outline Daycare Standards which have been developed nationally after consultation with staff are the basis for each project having its own daycare standards manual.

For further information contact:
Jim Jackson, Executive Director
Alzheimer Scotland - Action on Dementia, 8 Hill Street, Edinburgh EH2 3JZ, Scotland
Tel: +44 131 225 1453
Fax: +44 131 225 8748

Spotlight on a member group

The Romanian Alzheimer Society

Dr Catalina Tudose, President of the Alzheimer Society of Romania

A group of very enthusiastic professionals set up the Romanian Alzheimer Society, soon after the events of 1989 and the Society was officially registered on the 2nd of February 1992. From the very beginning the founders' efforts were supported by the World Health Organization, through its experts from USA and Belgium.

The essential goals of the Romanian Alzheimer Society are to increase the awareness of the population and of professionals in the recognition of these diseases, to improve the quality of care and to support the families in their desperate effort of caring for their relatives.

The role of professionals

The important contribution of physicians, nurses, psychologists and medical students in setting up a

Society like ours is something specific for all Eastern European countries because the population at large is not aware of its rights and has a poor understanding of community care. In order to achieve our goals we have had to adapt our strategy to Romanian economic and social realities.

Unfortunately, our health and social assistance departments are not prepared to assist the already increased number of old people – and certainly no dementia patients. For this reason, the Society has adopted a special plan for development: we have considered that the essential fact that has to be changed is the mentality of people, both professional and non-professional, and to develop first of all community responsibility. Therefore, even though our long term aims are very specifically related to people

with Alzheimer's disease and their carers, we decided to create a model in the community system and to promote social support for the general population of old people in the area. We aim to strengthen relations in the community and to find out, together with other members of the community, the priority needs of the elderly in the area. We have aimed to gradually identify the risk groups of people suffering with Alzheimer's disease and memory problems. Only in this way have we been able to develop special projects in which we have involved members of the community as volunteers. We have proved that people can begin to understand the role of the non-governmental organizations in the community and understand better the needs of people suffering from dementia in the community.

Care of the elderly

Another reason for developing a centre focused on promoting moral support for all old people first was the belief that we should not just help a small part of the population. At present most old people think they are also 'victims'. We will not have the support of the community as a whole unless we begin with some general programmes.

These ideas were, in fact, the result of conclusions provided by our first activity. This was the participation in the research done by the British organization, HelpAge International, at the request of the World Bank, regarding the assessment of the elderly situation in Romania (July – August 1992).

We have become very realistic and aware of our economic situation and it was also very useful to take into consideration the international conclusions regarding the care of the elderly: that maintaining people in their homes, in their natural environment, is the best solution from an economic as well as a

Our main plans for the future

- To set up new branches in other districts
- To organize new support groups and self-help groups for family members
- To improve the actual home help services and to create respite care service
- To set up a small department like a day-hospital for Alzheimer patients
- To publish the Romanian Alzheimer Review
- To organize training for carers in a systematic and continuous way
- To improve and to strengthen the collaboration with the governmental institutions as well as with other non-governmental organizations dealing with elderly problems
- To promote medical and social information regarding Alzheimer's disease and specific care, by publishing leaflets, drafting teaching tools, creating a 'hot line' programme for Alzheimer's and by obtaining broadcasts on TV and radio dealing with Alzheimer disease and other related dementias.
- To organize a national workshop with the assistance of ADI



For some elderly people the Alzheimer's Society is their only hope

district, a rural and mountainous area, another branch was set up. The projects here, though, had to be adapted to local conditions.

In June 1995 the Alzheimer Society organized a workshop during the National Psychiatric Congress organized in Piatra-Neamt. It was an opportunity to explain and to describe our activity to the medical public. This encouraged the formation of other branches in Constanta and Lasi. Meanwhile the number of elderly and family members especially have increased, due in part to publicity done in the past year; namely broadcasts on TV and radio, which led to many telephone calls.

From the very beginning the Romanian Alzheimer Society has been strongly supported by many similar organizations in the World. Alzheimer's Disease International has helped us very much by sending a lot of information on medical, scientific and managerial matters. All the ADI members have been close to us, encouraging us all along the way.

In 1994, in recognition of our work, we became a candidate member of ADI. In 1995 we were accepted as a full member.

medical point of view. As a consequence of this strategy we have developed a model community centre to meet the social and medical needs of elderly people greatly assisted by HelpAge International and the financial support of the European Community.

In January 1993, the Society set up the first two day centres for the elderly in Romania – in Bucharest and Galati. Each project includes a meals on wheels programme, home visits, centre activities, information and medical advice, and we initiated training programmes for volunteers.

We also published a nursing book for specific aspects of elderly and demented people care and we organized practical secondments for students from the Faculty of Social Assistance. In 1994 we organized the first support groups for Alzheimer family members and we initiated services such as home helps.

Spreading the word

The very good and impressive evolution of the projects in Bucharest and Galati inspired colleagues to imitate the initiative group. In Buzau

A Game of backgammon is welcome at the day centre



Meals on wheels are always on time





A family carer's story

By Mrs Jean Palmer of Picnic Point, New South Wales, Australia – family carer, Alzheimer's Association NSW Speakers' Bureau member and member of Bankstown Support Group

My husband, Arch Palmer, has Alzheimer's disease. He has had it now for 14 years. For six and a half years there was no diagnosis. It is a slow insidious disease which takes its toll on the sufferer and the family.

A respected man

I did not know what was happening to this man - my friend, my lover and essential part of our family life. Before retirement, Arch was a respected engineer in the printing industry. He was a good father and husband. He was a gregarious man and we had many friends. Our home was always open to any number of people for laughter, for discussion, for those wanting to exchange views, to people seeking Arch's opinion, seeking his insight into a wide range of questions.

How ironic it was that this man who was sought after because of his insight, his analytical ability, should develop a disease where this talent was the first thing he lost.

A once very capable man, Arch's memory became poor. His sense of direction deteriorated. At times his behaviour was erratic and unpredictable. But the greatest shock of all to me was his diminished intelligence; his inability to plan, to reason, to discuss logically as in the past.

Uncertain diagnosis

I complained to the medical people that something was wrong. They carried out tests to eliminate other conditions which might cause the deterioration (overactive thyroid, lack of vitamin B, brain tumour, depression, alcohol damage etc). All the tests were negative. No medical person would or could put a name to Arch's condition in the early stages. No one warned me by saying, 'Jean, prepare yourself, it

might be dementia, it might be Alzheimer's disease'.

Even today, there is still no one true test that can 100 per cent confirm a diagnosis of Alzheimer's disease - no X-rays, no blood test, no brain scan. It is finally only with an autopsy that this disease can be diagnosed with certainty.

I was desperate for an explanation. I haunted libraries to read the medical books - Alzheimer's disease kept erupting from the pages. My automatic response was to deny this. If the medical people couldn't put a name to the complaint, who was I to make the diagnosis?

Six and a half years later, in 1989, a medical assessment team said, 'It looks like Alzheimer's disease'.

Growing awareness

Since then, at least in New South Wales and many parts of Australia, there is much more awareness about Alzheimer's disease amongst both the medical community and the public. In some cases, it may still take six years to assess Alzheimer's disease. But hopefully, with this better understanding by all concerned and more sophisticated tests, the assessment of this disease or another type of dementia is now made much more quickly.

When a name was finally put to Arch's condition, I started to come to terms with it, to accept it, to know the road we were going down.

Alzheimer's Association

I was encouraged by my family to join the Alzheimer's Association. At first I was dubious. But there I found some strength. There I found that in a support group with other carers, people could come together to share their experiences, to cry, talk, get angry and be subjective. In the Association I found people who understood what I was going through.

A friend of mine makes the analogy between joining the Alzheimer's Association and a moving walkway, like those at airports. You join the Association and glance further down the walkway where there are people caring for their loved ones who are far more deteriorated than your loved one, and you say to yourself, 'My loved one will never get to that stage,' but slowly and surely, in most cases, your loved one does get to that deteriorated stage. Then you look back along the walkway and see people joining the Association just as you did all those months or years ago, and you're able to help them.

Love and encouragement

Arch has been in a nursing home now for several years. I couldn't continue the round-the-clock care he needed. He has greatly deteriorated, but still retains some of that wonderful spirit he had when he was a well man.

When I go to see him at the nursing home, I speak words of love and encouragement. It helps me, and I'm sure it helps him.

If you have Alzheimer's disease or any type of dementia in your family, or you know any family going through this tragedy, encourage them to join their local Alzheimer's Association. There they can talk over their problems and express their emotions. There they can get information and education on what is happening with the disease, what to expect, personality and behaviour changes, research progress, help with dealing with emotions, learning to relax, use of community services, managing legal and financial affairs and a host of other services.

Joining the local Alzheimer's Association will not eliminate the problems, but there you'll find understanding and emotional strength.

An overview of current research directions

Research into therapies for Alzheimer's disease

Dr Serge Gauthier

TACRINE AND RELATED DRUGS

In the December 1995 issue of *Global Perspective* we discussed the use of Tacrine and related drugs, known as cholinesterase inhibitors (CI), which slow down the breakdown of the brain transmitter acetylcholine (Ach). These medications aim at relieving symptoms of Alzheimer's disease (AD), at least temporarily. Many other classes of drugs are under development, and could eventually be combined with CI.

CHOLINERGIC DIRECT AGONISTS

These are medications that artificially replace Ach and directly stimulate receptors, specialized cell structures through which nerve signals are transmitted. Many different types of Ach receptors exist, and it appears that those called muscarinic type 1, if stimulated properly, could improve symptoms of AD. Drugs such as xanomeline, SKB202026 and miramiline belong to that class. Early reports suggest some efficacy on cognition and behavior, with increased sweating and syncope (fainting) as side-effects. Another type of Ach receptor is the nicotinic type, and ABT-418 is currently under testing.

OTHER TRANSMITTERS

Scientists are well aware that Ach is not the only transmitter affected by AD. Noradrenaline and somatostatin levels are reduced significantly. It is difficult to stimulate noradrenaline receptors only in the brain and avoid side-effects in the heart and blood vessels; an attempt to increase the release of noradrenaline was made

in AD using besipirdine (HP749), without success. Somatostatin is a peptide (a small protein) that does not easily get into the brain from the blood. A substitute for this peptide, Sandostatin, was to be administered to patients using a small pump implanted under the skin and connected to the brain ventricles through a shunt plastic tube, but pretesting for safety in monkeys showed Parkinson-like side-effects. A number of other transmitters and neuropeptides have been considered as candidates for therapy, but without much success so far. Ach thus remains the primary target for symptomatic treatment of AD.

STABILIZATION THERAPIES

There is much interest to go beyond transmitter replacement therapy and reduce the loss of brain cells and their synaptic connections, achieving a stabilization effect. This approach requires understanding of the etiology (causes) and pathophysiology (mechanisms) at play in AD. Numerous hypothesis over the years have led to use of aluminum chelation, monoamine-oxidase B inhibition, antiinflammatory drugs, nerve growth factor, acetyl-L-carnitine, lecithin, calcium channel blockers and vitamins administration. Many of these studies will be finishing in 1996 and exciting results may be available at a series of AD meetings this year, including Nice in April, Osaka in July and Jerusalem in October.

PREVENTIVE STRATEGIES

Now that we can identify some individuals at high genetic risk using the family history combined with apoE testing, we must find means to delay the appearance of AD symp-

toms. This may require preventive therapy with cholesterol-modifying drugs (since apoE carries cholesterol into the brain for the normal maintenance of nerve cell function). Other approaches under consideration include oestrogen replacement in post-menopausal women, anti-inflammatory drugs such as low dose prednisone, and vitamins C and E. Careful planning is under way prior to testing these agents in asymptomatic individuals selected for their genetic risk. Finally, large scale epidemiological research in the general population, such as the Canadian Study on Health and Aging, is increasing our knowledge of risk factors as well as protective factors in regard to AD, potentially leading to good advice for the aging population as a whole.

Dr Serge Gauthier is currently a member of the Research Policy Committee of the Alzheimer Society of Canada and served as Chairman of the Bio-Medical Peer Review Panel of that committee from 1989 to 1992

Alzheimer's disease exhibition

The Science Museum in London is running an exhibition throughout the summer aimed at raising awareness of Alzheimer's which, with over 390,000 current sufferers, is the single most common disease in Britain and the fourth major cause of death.

The exhibition was opened on 2nd May by actress Britt Ekland and Dr Martin Rossor, consultant neurologist at St Mary's Hospital and the National Hospital for Neurology and Neurosurgery.

An open invitation to the conference



Dear Colleague,

On behalf of the Local Organizing and Scientific Committees we take great pleasure in inviting you to join us in Jerusalem in October 1996 for the 12th International Conference of Alzheimer's Disease International.

Israel is proud to host this important international meeting, which will take place in the unique setting of Jerusalem, spiritual center for three great religions. The city offers a remarkable blend of ancient - with its numerous holy and historical sites - and modern - the beauty and convenience of a new city with all the necessary tourist facilities.

A highlight of the Meeting will be a reception by the President of the State of Israel, Mr Ezer Weizman and Mrs Weizman, for the heads of the international delegations of the National Alzheimer's Disease Association.

We hope that you will join us and take the opportunity to participate in an extensive professional, medical and scientific program, as well as to travel throughout the country. A specially-arranged program of tours will enable you to visit archaeological and holy sites throughout Israel, including Christian sites in the Galilee, as well as Egypt and Jordan. The mild autumn weather will make a visit to the Dead Sea (the lowest spot on Earth) with its invigorating spa facilities of special interest. A visit to the Red Sea resort of Eliat offers water-sports and relaxation in the autumn sunshine.

We look forward to welcoming you to a stimulating meeting and wish you an enjoyable stay in our country.

Dr Shmuel Moran
Organizing Committee
Chairperson

Prof. Amos D Korczyn
Scientific Committee
Chairperson

Ruth Goldberg
Alzheimer's Association
of Israel, Chairperson

12th International Conference of Alzheimer's Disease International

Jerusalem, Israel
8-11 October 1996

PROVISIONAL TIMETABLE

Tuesday October 8

Afternoon Registration and distribution of
Conference material
Evening Informal Get-together

Wednesday October 9

All day Conference Sessions
Evening Social event

Thursday October 10

All day Conference Sessions
Evening Festive Dinner (Optional)

Friday October 11

Morning Conference Sessions
Afternoon Departures
Post-Conference Tours

PROSPECTIVE SPEAKERS

T Arie, UK
S Arkin, USA
F Boller, France
H Brodaty, Australia
V Chandra, India
J Chapman, Israel
A Croy, Austria
M Davidson, Israel
K Davis, USA
P Edwards, UK
T Erkinjuntti, Finland
R Friedland, USA
T Gabryelewicz, Poland
S Gautier, Canada
N Graham, UK
G Grunfeld, Israel
J Hay, UK
F Jordan, Australia

Z Khachaturian, USA
A D Korczyn, Israel
J Krecke, Luxembourg
L Leduc, Canada
G Livingstone, UK
M Livni, South Africa
N Lombardo, USA
S Lovestone, UK
D Marin, USA
L Mendoza, Mexico
D M Michaelson, Israel
B Moss, Australia
J Mintzer, USA
M Pontecorzo, USA
A Roses, USA
D Schnit, Israel
A Shapira, Israel
P St. George-Hyslop,
Canada
M Unwin, UK
G Wilcock, UK

MAIN TOPICS

- Education for the patient, the family, the community
- Genetic Counselling: Should it be done?
- The Rights of the Demented Patient, Legal and Ethical Issues
- Treatment of Alzheimer's Disease - Now and in the Year 2000
- Organizing a Safe Environment
- The Wandering Patient - Doing Right or Doing Wrong
- Care for the Caregivers - Helping Families Cope
- Fund-raising for Alzheimer Associations
- The Right Nursing Home: Cost/Quality Choice
- Social Policy: Intergenerational Support or Conflict
- Development of Services and Support Groups
- Molecular Biology and Genetics of Dementia
- Update on Drug Studies: Hope or False Hopes
- Brain Imaging: Do All Patients Require it?
- Care and Caring

For further information, contact the 12th ADI Secretariat, PO box 50006, Tel Aviv 61500, Israel.

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