Alzheimer's Disease International

Global Perspective

VOLUME 8 NUMBER 1 MARCH 1998

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

ADI to launch Alzheimer University

The Alzheimer University – a series of workshops to help new and potential members create a strong association – will be piloted in London in April. The course has been developed by ADI in collaboration with the UK's Open University. Twelve delegates from Turkey, the Czech Republic, Greece, Cuba, Belarus and Ecuador will be sponsored by ADI to attend.

The workshops will give participants the tools to identify their aims, involve people, provide information, raise money, raise awareness and influence public policy. They will enhance participants' sense of the value of their work in supporting people with dementia and their carers.

Funding for the pilot has been raised from donors in the UK, but an application for funding for a further two years has been submitted to the UK Lottery Board. There are plans to develop the course for more experienced associations. Brian Gearing, former senior lecturer in the School of Health and Social Welfare at The Open University, said 'as well as strengthening their own associations, people who have completed the training programme will be in a better position to share their expertise with other organisations which are similar in culture and language'.

ADI assists in the formation of a new Alzheimer's association

Birth of Turkish association

An early press conference for the Turkish Alzheimer's Association, attended by Dr Nori Graham, chairman of ADI

The growing need for care of people with Alzheimer's disease brought health professionals and caregivers together to start an Alzheimer's disease association in Turkey. The silent epidemic of the world has been more silent in Turkey, but changing life styles and increased awareness about public health issues has brought dementia to the attention of physicians and the public. The Turkish Alzheimer Association was officially founded on October 3 1997 by 25 health care professionals and caregivers. The main aims of the association are raising awareness, educating professionals and caregivers, providing better care, supporting carers and encouraging research.

The inaugural meeting of the Turkish Alzheimer's Association was held in Istanbul, 27-28 November 1997. We were honoured by the presence of Dr Nori Graham, chairman of ADI and the well known Alzheimer's disease researchers, Dr Marsel Mesulam, Dr Sandra Weintrub and Dr Albert Hofman. The audience on the first day were mainly health professionals from all over Turkey. The attendance rate was striking for a first meeting, 450 in total. The meeting was highly stimulating and motivating for everybody. Nearly 200 professionals applied for membership by the end of the day.

The organisers of the meeting were very excited about the impact of the meeting on caregivers. On the second day a half day symposium was held for carers. More than one hundred carers participated and became part of our association by the end of the day. With their needs and enthusiasm we hope to fulfil the aims of our association. For them, even meeting other people with the same problem was a relief, the second relief came when they realised that from then on they were part of an association which could provide solutions to some of their problems.

Now our association has a fully equipped new office (with kind support from ADI) and a full time employed secretary. We already have three sets of brochures about Alzheimer's disease that are being distributed all over the country and we have a toll free telephone line which provides information about dementia and our association.

A number of TV and newspaper interviews were published along the way. We have formed a social committee which we hope will be very active in raising money, and we started our first official self-help group in January. The second set of brochures about practical management of common problems are on the way. We hope to make fast progress thanks to ADI showing us the way ahead and their support.

IN THIS ISSUE

The Alzheimer's Disease International website can be found at: alzdisint.demon.co.uk

ANNOUNCEMENTS

CONFERENCES

1998

March 9-10
Alzheimer's Disease in Europe
Developing Policy & Practice
Dublin, Ireland
TEL: +353 1 671 9566
FAX: +353 1 671 9818
EMAIL: eireann@iol.ie

April 15-18
5th international Geneva/ Springfield Symposium on Advances in Alzheimer Therapy
Geneva, Switzerland
TEL: +1 217 782 7711
FAX: +1 217 785 4413
EMAIL: ogden@wpsmtp.siumed.edu

April 23-25
The Alzheimer Society of Canada's 20th Annual Conference
Vancouver, British Columbia
TEL: +1 416 925 3552
FAX: +1 416 925 1649
EMAIL: education@alzheimer.ca
WEB: www.alzheimer.ca

May 7-9
Alzheimer Europe 8th European Meeting
Lucerne, Switzerland
TEL: +41 41 312 18 12
FAX: +41 41 312 18 13
EMAIL: ctlag@bluewin.ch

May 14-15
1st International Conference on Family Care
Caring for Carers
London, UK
Contact: Carer's National Association
TEL: +44 171 490 8818
EMAIL: icc98@carersuk.demon.co.uk

May 18-20
International Council for Global Health Progress
Worldwide revolution in longevity and quality of life opportunities, challenges and responses
Paris, France
TEL:+33 1 45 59 36 77
FAX: +33 1 45 59 38 85
EMAIL: cipgs@club-internet.fr

July 18-23
6th International Conference on Alzheimer's Disease and Related Disorders
Amsterdam, The Netherlands
TEL:+31 20 5040 202
FAX: +31 20 5040 225
EMAIL: alzh98@congrex.nl
WEB: www.congrex.com/alz98/

July 26-29
7th National Alzheimer's Disease Education Conference
Creating opportunities, making connections
Indiana, USA
TEL: +1 312 335 5790

September 13-18
'Aging 2000' A Comprehensive Approach to Mental Health
Munich, Germany
TEL: +49 30 23 82 69 00/13/20
FAX: +49 30 23 82 69 40
EMAIL: ipa@kit.de
WEB: www.kit.de

September 19-25
3rd Congress of the European Federation of Neurological Societies
Sevilla, Spain
TEL: +34 5 422 61 60
FAX: +34 5 422 80 70
EMAIL: viajes.tavora@unida.com

September 24-27
Alzheimer's Disease International 14th International Conference
Dementia the Global Challenge
Cochin, India
TEL: +91 488 522939
FAX: +91 488 522347
EMAIL: alzheimr@md2.vsnl.net.in
WEB: www.alzheimr.com

December 10-13
4th International Conference on Long Term Care Case Management
Which Way to Quality?
San Diego, USA
TEL: +1 415 974 9600
FAX: +1 415 974 0300
EMAIL: info@asa.asaging.org
WEB: www.asaging.org

International directions

ELIZABETH RIMMER, SECRETARY-GENERAL

I have just returned from a very productive week in Cochin meeting everyone involved with the 14th annual conference preparations. Cochin is a modern, bustling, expanding city with a population of 1.6 million – a wonderful venue for our conference and there is lots to explore in the surrounding countryside. Dr Jacob Roy and Dr Vijay Chandra have put together a stimulating programme which highlights the global nature of dementia and the differences in attitudes to it which exist worldwide. The final announcement will soon be with you all.

The conference is of special importance to ADI and ARDSI as it is the first to be held in an Afro/Asian country and could do so much to raise awareness about dementia in India. I met a number of businessmen, town officials and government employees who had never heard the word and were truly surprised when I told them that there were an estimated 3 million people with dementia in India. Everyone I met was extremely proud that Cochin will be hosting its first international conference. Your participation in this conference is crucial to its success and you will be assured of a very warm welcome and a unique learning experience.

PUBLICATIONS

The Best Friends Approach to Alzheimer's Care
By Virginia Bell and David Troxel. This comprehensive program builds on a person's remaining strengths and abilities and uses positive strategies that are easy to learn and put into practice. $24.95. Video also available $45.00
For orders in Europe/UK:
TEL: +44 171 833 2307
FAX: +44 171 837 2917
For orders in rest of world:
TEL: +1 410 337 9585
FAX: +1 410 337 8539

Alzheimer's Disease in Primary Care
By S Gauthier, A Burns & W Pettit. Includes clinical diagnosis, investigations, treatment, patient and family support and future prospects. Special offer to members £5.00 until end of April (normally £9.95). Contact Adele Nicolaou at Martin Dunitz Publishers, London quoting Global Perspective.
TEL+ 44 171 482 2202
FAX: +44 171 267 0159
EMAIL: info@dunitz.co.uk

State of the Art in Dementia Care
Edited by Mary Marshall, £14.00. This book offers accounts of developments in dementia avoiding technical language and jargon. Topics range from how dementia is experienced by the individual to wider policy and planning issues. For details of this and other publications please contact the Centre for Policy on Ageing, London
TEL: +44 171 253 1787
FAX: +44 171 490 4206.

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 you 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.

Testimonio

ELIA LYNE DE MENDEZ· PRESIDENTA DE AVAES · CD. VALLES · MEXICO

After years of different diagnosis and treatments, this carer's husband was finally diagnosed as having Alzheimer's disease. What follows is a story of courage and determination. She resolved to begin a self-help group in her city and is now chairperson of a chapter in Mexico.

Fueron varios años de peregrinar por diferentes ciudades, clínicas y médicos buscando la salud de mi esposo, pero veíamos con tristeza que él iba empeorando a diario, sin tener respuesta a los diferentes diagnósticos y múltiples tratamientos que se le administraban. Yo sentía que mi esposo caía en un abismo profundo y negro y no podía ayudarle a detenerse...fueron tiempos muy angustiantes y dolorosos. En 1985, desesperados y con la ilusión de encontrar una cura, nos dirigimos al 'Diagnostic Clinic of San Antonio'. Paulatinamente, bajo el cuidado de un prestigiado neurólogo, las reacciones de inestabilidad, agresividad y violencia disminuyeron bajo el tratamiento. Lo primero que me dijo el Dr. fué que alejara a mi esposo de toda responsabilidad. Esto no fué fácil ya que toda su vida él había sido un hombre muy trabajador y responsable. Al mismo tiempo empezaron a prepararme para la situación que tendría que enfrentar en un futuro. En 1988 tuve mi primer contacto con una asociación donde me sugerieron que formara un grupo de apoyo en esta ciudad. En esa época yo no tenía conocimientos de que hubiera en nuestra ciudad personas con problemas de demencia. En 1994, me dí de cuenta que dos de mis amigas estaban pasando por la situación que yo viví y fué en esos momentos cuando me decidí a organizar el primer grupo de apoyo con la ayuda de AMAES. Mi propósito fué ponerme una meta cada año, con el favor de Dios y la colaboración de mis colegas, se han ido logrando. Quedo agradecida a todas esas personas que creyeron y confiaron en mí y que me han apoyado en esta misión, así como aquellas personas que nos abrieron su mente y corazón para escuchar el mensaje que dábamos del conocimiento de esta triste enfermedad, que cada día va alejando a nuestro ser querido de nuestro lado hasta convertirlo en un extraño y no podemos evitarlo; pero sí podemos ayudarle a llevar una vida digna y humana. Gracias a Dios puedo decir que he aprendido a aceptar la situación que estoy viviendo y que gracias a AMAES el camino ha sido menos doloroso ya que llegué a conocer la enfermedad y sus consecuencias, así como la manera de manejarme para poder ayudar a mi esposo. Esto es lo que me ha motivado a llevar el mensaje a las personas que tienen un enfermo con problema de demencia...que no es locura, mucho menos una vergüenza y que siempre tendrán ayuda cuando la necesiten.

Is quality an elephant?

BY JIM JACKSON, EXECUTIVE DIRECTOR, ALZHEIMER SCOTLAND ACTION ON DEMENTIA

Last year members of ADI were surveyed about the techniques that are used in their countries to measure effectiveness and quality of services. Replies were received from 13 countries which are broadly representative of the ADI membership.

Three basic approaches to assessing quality were reported by members. The first might be more accurately described as an assessment of quantity. This is to monitor the records of the number of service users, the frequency of the service and descriptions of the services provided.

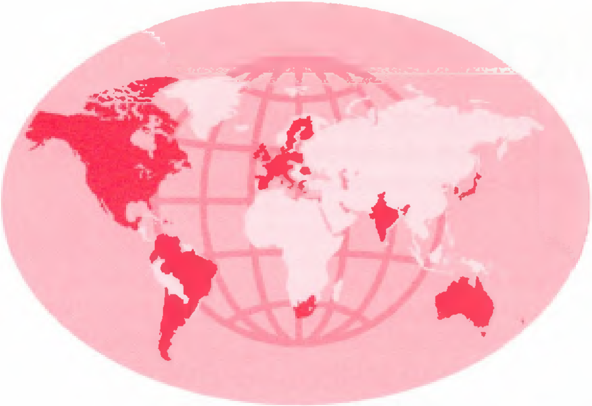
The second approach is to ask service providers, either staff or volunteers, for their feedback about how well a service is being provided.

The third approach is to ask the family carers for their feedback A fourth approach to quality assessment which requires a much greater investment of time and resources is when standards are set for particular services. Specific guidelines are produced and quality assurance procedures are implemented.

The survey showed that most national Alzheimer's associations are only using very basic approaches and techniques. This is understandable when there are more pressing priorities for associations that are under-resourced and fighting for their survival. But is this acceptable for well established Alzheimer's associations? Surely we should be leading the way about how to provide good quality services and how to demonstrate that they are of a high standard.

Quality is a bit like an elephant. We all know one when we see one but it can be difficult to describe in words. Most of the approaches identified in this survey don't actually define quality but assume that the available information can be interpreted to make a judgment about quality. The problem is that this assumes that we all have the same understanding about what is quality or an effective service. At the 1998 ADI Conference a workshop will be held to explore alternative definitions of quality and learn about different approaches and techniques. It will be an opportunity to share experiences about the difficulties of applying quality management to dementia care.

I look forward to seeing you in Cochin.



Members' Forum

Falko Wiedemann, Sabine Jansen and Hans-Jürgen Freter of Deutsche Alzheimer Gesellschaft

GERMANY

In Germany there are about 800,000 people with dementia – in 2005 there will be 1.2 million. Deutsche Alzheimer Gesellschaft, founded in 1989, is the national organisation of more than 30 local Alzheimer's associations and a larger number of self-help groups. The net of organisations is more developed in urban areas, and there are special efforts to improve services in rural areas and in the regions of the former Deutsche Demokratische Republik. Deutsche Alzheimer Gesellschaft is a member of Alzheimer's Disease International and Alzheimer Europe. Deutsche Alzheimer Gesellschaft moved its headquarters from Stuttgart to Berlin in July 1997. In an office situated at the centre of Berlin, Sabine Jansen and Hans-Jürgen Freter (social worker and sociologist) are working as executive directors, assisted by Andrea Kuenemund and Falko Wiedemann, who are responsible for computer tasks. The office supports regional organisations, provides general information about Alzheimer's disease, supplies booklets eg about the organisation of family support groups, dementia care in nursing homes and about questions concerning the German social security system; a booklet about legal and financial issues is in preparation. Since 1997 the quarterly newsletter Alzheimer Info publishes articles about medical issues, new models of therapy and caring, problems of family carers and reports about the activities of the local Alzheimer's associations. Deutsche Alzheimer Gesellschaft held its first national congress in September 1997 in Stuttgart with more than 1,000 participants. The next national congress is scheduled for September 1999 in Berlin. Speakers emphasized the high priority of developing networks of family support groups, increasing the number of memory-clinics which are ready to make an early diagnosis, of establishing small dementia units in nursing homes, and of better training for all professions involved in dementia care. In October 1997 Deutsche Bundestag discussed a report about the situation of dementia patients in Germany. Public awareness is growing, but much remains to be done in the country where Alois Alzheimer was born.

HANS-JÜRGEN FRETER/SABINE JANSEN

GUATEMALA

Under the joint sponsorship of Ermita and ADI, Laura Trejo of the County of Los Angeles, Department of Mental Health visited Guatemala on 1-3 September 1997 to provide training and other consultative services. The following activities were undertaken:

Dementia care workshop: this was offered to a group of nurses, social workers and family caregivers all involved in direct care. Topics on this 12 hour course included an introduction to dementia disorders, neurological changes, mental health issues for patient and caregivers, behaviour management, communication and maximizing physical function in dementia patients.

Television interview about Alzheimer's disease and its impact on families.

Support group visit: a visit to Ermita's ongoing psycho-educational support group. Concerns raised included family conflict, issues of social stigma related to inappropriate behaviour by patients in public, socio-economic concerns of primary caregivers and difficulties in assessing health and other needed services.

Meeting with medical scientific board members: discussed several potential areas for further exploration including co-sponsoring a national or regional conference on geriatric care with emphasis on the dementias, establishing dialogue with the local University on developing a Masters degree in Gerontology and developing a specialized course on dementia care for nurses already in this field.

The visit was a great success and consensus was reached on what needed to be done in order to move forward, including: support group development, consultation and training on establishing protocols for a differential diagnosis (and adapting this within different cultural groupings), curriculum and

Ermita's carers support group

training development for professional groups, developing educational activities for family caregivers, availability of educational materials and assistance with funding sources.

HONG KONG

Our newsletter was distributed to all our members at the end of December 1997. As always, our aim is to provide a wide range of topics concerning the care and treatment of people with dementia. Topics included an article by Dr K K Mo (geriatrician) on the different dementias and treatment; a message on how to care for those with incontinence problems at home and information on the respite care services (day and resident) organized by the Helping Hands and the Hong Kong Christian Service which also provide a short break for carers. The latter is a newly launched half day respite service (under pilot study) for people with dementia living in the community. Experiences were also shared by an attendant who has just completed a carer's training course. Starting from this issue, we have opened up a new column for answering carers' problems e.g. how to handle accidents at home. We were also pleased to announce the newly elected executive members for 1998 and the winners of the 'smart memory contest'. Our last public activity was to organize an open forum on World Alzheimer Day. We invited the legislative councillor (Chairman of the Committee for Elderly Care) and other politicians as well as those with dementia and their family carers to discuss the issue of developing special care and services for people with dementia. Finally, Dr C S Yu (Chairman of ADA) briefed us on his trip to the International Conference in Helsinki.

SOUTH AFRICA

Arrangements for hosting the 15th ADI International Conference in Johannesburg in September 1999 are well under way. ARDA delegates to last year's conference in Finland distributed preliminary announcements to conference delegates. A request for speakers and exhibitors has been made. Global Conferences of Cape Town have been appointed as the conference secretariat. For details please contact: tel +27 21 762 8600, fax +27 21 762 8606, email adi99@globalconf.co.za, web http://www.globalconf.co.za/adi99

AUSTRALIA

Franceska Jordan, chairman of the former ADI Education services committee, has been awarded the AM for her services to the Alzheimer Association of Australia. ADI congratulates her on this honour.

JAPAN

On 29 November 1997, AFCDE held the 14th annual meeting in Tokyo on improvement of social services for people with dementia and their families. Approximately 1,000 people attended from all over Japan. Topics for caregivers included counselling/help line services, how to improve these facilities as well as how to obtain useful information from medical and social services in the community and disseminate this information. Prof K Nakazima of Health Sciences University of Hokkaido and Prof A Karasawa of Seitoku University commented on the reports and discussion.

Become an associate member of Alzheimer's Disease International

Individuals and organisations can become associate members and receive the newsletter and notice of events and publications

I wish to become an associate member of Alzheimer's Disease International

Name ....

Address ....

....

....

Much of ADI's funding is provided by our member countries. However, national associations have enormous demands on their limited resources, so ADI continues to rely on donations from individuals and organisations. There is no fixed subscription for the newsletter, all donations are welcome. (Member countries and officers of ADI receive the newsletter free.)

I enclose payment of ☐ £10/$15 ☐ £25/$40 ☐ £50/$75 ☐ Other ....

Payment can be made by cheque or banker's draft in either US dollars or Sterling, to Alzheimer's Disease International, 45/46 Lower Marsh, London SE1 7RG

The beginnings of the Czech Alzheimer Society

Caring for caregivers in the Czech Republic

BY DR HANA JANECKOVA, BOARD MEMBER OF CZECH ALZHEIMER SOCIETY, PRAGUE

AFTER Poland and Romania, the Czech Republic is the third post- communist country to join ADI. Compared to other self-help groups which sprang up very quickly after the revolution in 1998, the rise of the Czech Alzheimer Society (CALS) has taken some time. The new organisation came into being in February 1997. But the start of CALS was very quick and we have many activities and plans for the future. How has this happened?

Unsatisfied need

The situation of the elderly in the Czech Republic was not good. The most frail groups like people with dementia suffered from the lack of accessible institutional and home care services. Dementia was contraindicated for admission to institutions such as long term hospitals and old peoples homes. If the care was provided there, it was minimal, and led to passivity, deprivation and total deterioration earlier than was necessary. Most people with dementia stayed with their families which then became isolated, relatives fully devoted to care did not have enough information, rest or sufficient social support. Early attempts to establish a carers group were hampered by the sometimes indifference of the families.

Important help from abroad

The story started in Diakonia, with the development of 'Family Clubs' in 1995. A few family carers together with professionals met at several seminars. ADI heard about this activity and recommended Noreen Siba, (former executive director of ADS, UK) who used to come to Prague frequently, to support this activity. We organised a meeting of participants and other interested people – about 40 – with Noreen in May 1996. She informed us about British and ADI experience with establishing a new Alzheimer organisation. The following visit of Noreen to Prague in autumn 1996 was the most important one. She was a good facilitator at the meeting of about 20 people who were interested in establishing a new association. Dá˚a Niklová, a student of social work at Charles University, made a very important decision to undertake the organisational work and administration. Another important offer came from Iva Holmerová, a physician and a director of the Centre of Gerontology, who offered the use of one room in this centre and a telephone for the Czech Alzheimer Society. From this moment the work could start. Registration came in February 1997, our help line started in April. Education of volunteers was prepared and a course 'Working with dementia' with Jitka Zgola, an excellent occupational therapist from Canada, was organized for professional caregivers. Later CALS applied for provisional membership of ADI. We started to disseminate information about the existence and message of CALS through the media. The translation and dubbing of the videotape *Care to make a difference* (produced by the Alzheimer's Disease Society, UK) was made thanks to the grant of the Ministry of Health. Brochures about CALS and about Alzheimer's disease were published with the help of pharmaceutical companies. And finally the ADI booklet *Help for caregivers* was translated from English and given to carers. In September 1997, CALS was accepted as a provisional member of ADI.

Experience from the non-governmental sector

Our experience from the work in Diakonia, the Gerontological Centre and the Gerontological and Geriatric Association was very useful. It helped us in educating people, fundraising, management, marketing and volunteering. In our situation, where existing state institutions are unable to offer much support to people with dementia and their families, the spontaneous and enthusiastic activity of our new association has brought its first fruits in the form of help to the caring families and in involving volunteers.

Interdisciplinary team collaboration

While early attempts to create a carer's organisation were made by isolated physicians and were ignored by families, this time the initiative came both from physicians, other professionals and carers. This interdisciplinarity was very useful in opening horizons for new people from various fields, combining different skills and balancing various opinions. CALS proved to be very efficient in helping carers. A broad awareness campaign resulted in many caregivers contacting the Alzheimer's centre for the first time. Let's hope that more and more of them will soon recognize that CALS is a meaningful and useful organisation, helping people with dementia and their families.

14th International Conference of Alzheimer's Disease International

There are in excess of 60 million people in India over the age of 60, by the end of the century predications are that India will have the largest elderly population in the world. There are currently 3 million people with dementia. Despite the scale of the problem, awareness of dementia amongst professionals and the general public is low. There is little support available to carers apart from that offered by ARDSI (Alzheimer's Disease and Related Disorders Society of India). The conference will help to raise awareness and highlight the growing social and economic challenge dementia poses for India. Plenary, concurrent and workshop sessions will include epidemiology, caring strategies, advances in research, diagnosis and treatment and the role of Alzheimer associations. A warm welcome awaits you in Cochin and your support by attending will be greatly appreciated.


Staff and clients of the Urban Dementia Services Centre, Cochin

Conference programme

For more information please visit the conference web site www.alzheimr.com
or contact Dr Jacob Roy, Organising Secretary, PO Box 53,
Kunnamkulam, Kerala 680 503,
India
TEL: +91 488 522 939
FAX: + 91 488 523 801
EMAIL: alzheimr@md2.vsnl.net.in

Poem

KATHLEEN POTTS, AUDAS, URUGUAY

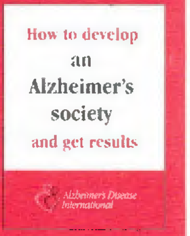
Who's this in the mirror
Keeps talking to me?
I don't recognize her,
Whoever can she be?
They say it's cold outside
But I am feeling hot,
I really cannot tell if it's spring,
summer – or what.
I don't know who I am
Or who now lives with me,
Who it is that cares for me
So very tenderly.
I can tell you my name,
My age I do not know,
If I have a family
Or if I live alone.
I feel so insecure,
I know there's something wrong,
I'm really scared at times
Won't someone take me home?
You must use your memory,
Because I have lost mine.
You really must help me
Almost all the time.
Tell me, where is my home?
'Twas such a happy place;
I want to go back there
And see my mother's face.
I'm not a piece of rag
that you can just discard,
I have my feelings too,
So please don't be too hard.
But when I go outside
I can't find my way back,
Won't somebody help me
And show me the right track?
And if perhaps I've changed
My personality,
I'm still a human being,
Remember that of me.

Alzheimer's Disease International

Booklets

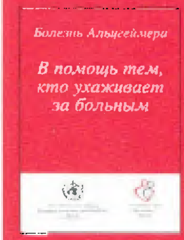
Available in English and Spanish

How to develop an Alzheimer's society and get results
Creating an Alzheimer's society is the most efficient way to achieve help for the largest number of people



Starting a self-help group
Produced by carers with experience of self-help groups from around the world

Help for caregivers
Useful and concrete information on how to care for someone with dementia. Also available in Arabic, Danish, Hebrew, Japanese, Russian and Spanish.



Factsheets

- **Prevalence of dementia**
- **Organisation of a prevalence study**
- **Reasons for prevalence studies**
- **Demography of ageing around the world**

All publications are free of charge from the secretariat

The dementia of Parkinson's disease

DR D PALEACU AND PROF A D KORCZYN
DEPT OF NEUROLOGY, ICHILOV HOSPITAL, TEL AVIV

In 1817 James Parkinson described the disease which now bears his name as an entirely motor disorder, "the senses and the intellect being unimpaired". However, this original statement has been challenged and since proven to be untrue.

Cognitive impairment is a common feature of Parkinson's disease (PD) and dementia has been diagnosed in 30-80% of PD patients according to different studies. (The differences result from various techniques of diagnosing it and the selection of patients who were studied.)

Symptoms

Patients with PD have a characteristic tremor, as well as slowness of movement (bradykinesia), increased muscle tone called rigidity and altered postural reflexes that can cause frequent falling.

It is quite legitimate to conceive that a slowness of movement (bradykinesia) would be accompanied by a slowness of reasoning (bradyphrenia) but these two characteristics frequently occur independently of each other.

Types of dementia

All patients with dementia, regardless of cause, by definition have memory problems, as well as other cognitive and affective deficiencies. There are two types of dementia, a 'cortical' type and a 'subcortical'. Clinically and pathologically, the dementia of PD has been classified with the 'subcortical' dementias. These are characterized by a short term memory deficiency, poor concentration as a basis for bradyphrenia, impaired visuospatial functions and depression (expressed in most cases as dysthymia, a slight form of depression, rather than major depression) in the affective area. Language praxis (translating ideas into actions) and comprehension processing are in general preserved, unlike in cortical dementia (whose prototype is Alzheimer's disease (AD)).

Some studies found a weak or no correlation of Parkinson's disease with cognitive impairment. Dementia is usually a feature that appears late in its course. It is also important to differentiate between dementia and pseudodementia (cognitive impairment due to severe depression) or between cognitive impairment of dementia and the psychotic features or confusion which can be associated with anti-PD medication.

Pathology

Pathological changes in the brain associated with dementia in PD include the neurofibrillary tangles and senile plaques, which are typical of AD. Some authors found that the prevalence of Alzheimer pathology is increased six times in the brains of patients with PD and, therefore, a link between the two conditions has been proposed. However, a study investigating the prevalence of the beta-amyloid (an abnormal protein) deposits which are a key feature of AD, did not find a significant difference between PD and control brains. Also, the allele E4 variant of apoliprotein is associated with AD, but not PD.

Treatments

One of the methods of treating PD is to increase the brain dopamine content using levodopa and dopamine agonist drugs. Although these drugs improve the motor deficits of PD, they may cause hallucinations or even frank psychosis. The treatment of psychosis or hallucinations is done by adjusting the levodopa or dopamine-agonist dose or withdrawing anticholinergic (antitremor) medication. Traditional neuroleptics in small doses and lately risperidone, clozapine and olanzepine (with lower propensity to extrapyramidal side effects) can be used to control psychosis.

EU-INDODEM STUDY

Dr Martin Prince, epidemiologist based at the London School of Hygiene and Tropical Medicine, London, has submitted an application to the European Commission to fund the EU-INDODEM project. ADI and ARDSI (Alzheimer's Disease and Related Disorders Society of India) are project partners (in addition to other institutions in Europe and India). The project is a cross national EU/India study of the social and economic impact of dementia in the community to determine the age specific prevalence of dementia in India and compare this with the situation in Europe. A consensus conference is planned for the Cochin conference to discuss the initial work of the project. The application for funding is currently pending but the outcome will be known by the summer.