Global Perspective

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A Newsletter for Alzheimer's Disease International (The International Federation of Alzheimer's Disease & Related Disorders Societies, Inc.

The Way It Works: The International Conference and the Annual Meeting of ADI Council

Alzheimer's Disease International under its Bylaws holds a Council Meeting each year. By tradition, it is held in September, and is hosted by a different ADI Member country each year. Over the years the event has grown into a full Conference, in addition to the Annual Meeting.

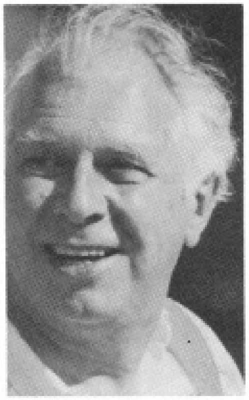
There is always a medical and scientific component which provides an update on Alzheimer research. Sessions for and by professional care providers and representatives from related fields (financial & legal services advisors, architects, educators, etc.) also participate.

People from all over the world are invited to present papers and/or attend the Conference. It has become a significant international event that helps raise awareness about Alzheimer's disease in the host country and sends a message worldwide about the growing unified effort that stands by persons with Alzheimer's disease and their families.

The ADI Annual Meeting of Council is essentially a business meeting. Members are represented by one person who sits at the Council table and is designated the voting delegate. Three additional delegates may attend as observers with a reasonable right to be heard, but not to vote.

Countries interested in becoming members of ADI may send three representatives to attend the Council Meeting as observers, but they may not vote.

Compelling Speakers & Program to Highlight ADI's 8th International Conference



Dr. Franz Baro, Chairman of the 8th International Conference Organizing Committee

ADI's 8th International Conference Organizing Committee has outdone itself in creating an exciting, highly informative and enjoyable program for the three-day Conference in Brussels, Friday through Sunday, September 25-27, 1992, held prior to ADI's annual meeting on the 28th.

Speakers for the opening session at the Headquarters of the European Community in Brussels, will include: Princess Yasmin Aga Khan Jeffries, President of ADI; Dr. Luigi Amaducci, University of Florence, Studio Multicentrico Italiano Sulla Demenzia, SMID (Italy); Dr. Peter Whitehouse, University Hospitals of Cleveland Alzheimer Center (USA); Drs. J. Hunter and A. Baert of the European Commission; R. Chanterie, of the European Parliament; L. Onkelinx, Belgian Minister of Health; and J. Sampaio Faria of the World Health Organization. Simultaneous translation in English, French and Dutch will be offered.

"Sharing our Programs" will occur when ADI member societies report on their program activities on Friday afternoon.

Saturday morning will offer workshops on: Basic Research, Neuropsychological Assessment, Psychomotor Rehabilitation; Guidelines for Care; Respite Care; Terminal Care; Architecture & Environment; Dementia & Family Practice, and more.

The Academic Session on Saturday afternoon,: "Strengthening the Caregiving Family" will include: Dr. Marcia Ory of the National Institute on Aging (USA), and Dr. Kristien Haepers (Belgium) and Dr. J. Kickbusch of the World Health Organization. Simultaneous translation in English, French and Dutch will be offered.

On Sunday afternoon, the Belgian Minister of Health, and Jerome H. Stone, Founding President & Honorary Chairman of the Alzheimer's Association (USA), will speak at the closing session. And, Reporteurs will give a round up critical synthesis of the congress.

In This Issue. . .

When ADI Meets in Brussels...

In 1991, ADI Standing Committees met to discuss their aims and activities during the 7th International Conference and Annual Meeting in Amsterdam. They will move their agendas forward when they reconvene in Brussels, in September, 1992.

The Public Relations Committee will review ADI's new logo and brochure; and discuss opportunities for promoting ADI's 10th International Conference in 1994.

The Education Committee will discuss a register of educational activities in member countries (noting availability of materials in different languages).

The Medical & Scientific Advisory Committee will review its goals and discuss recommendations for a significant Conference suggested for 1993.

The Public Policy Committee aims to encourage governments to recognize the needs of families and patients, and to develop policies to meet these needs."

The Conference Committee will review Members' applications to hold future ADI conferences in their countries. The Committee also will review protocols for Members holding ADI Conferences.

The Bylaws Committee recently distributed updated Bylaws, and will hear any recommendations for amendments, and move them for review and approval.

The Membership Development Committee will have at least three applications for membership to review. The applicants are national Alzheimer societies established and operating in Brazil, Israel and Japan.

The Patient & Family Services Committee last year established its aim to promote the exchange and documentation of information on services for people with dementia and their families. The Committee plans a Good Practices Data Bank as its first project.

Good Practices Data Bank

Alzheimer's Disease International is aiming to build up a library of good practice on services relevant to Alzheimer's disease carers and sufferers. The sort of services we are interested in are: How to run a self-help group; Successful sitting or day care formulate; Holidays and residential or nursing care, with a premium on innovation. Publications and audio-visual material along these lines should be sent to: Rachel Billington, Deputy Secretary, Alzheimer's Disease International, 919 N. Michigan Avenue, Chicago, Illinois 60611, U.S.A. Local language material is acceptable so long as translation is permissible. This material will be stored in the special ADI Section of the new Benjamin Green-Field Library in Chicago. In our next newsletter, we would hope to publish a list of material received which would then be made available to any country working along these lines.

Danes Respond to Alzheimer Challenge in the ADI Tradition

Alzheimer Foreningen (Danish Alzheimer Society) July 1992—Earlier this year, the Danish Alzheimer Society passed its first anniversary. With a membership approaching 1,000, the Society has already grown larger than many other Danish patient organizations. For the small handful of enthusiastic volunteers who started the organization, it has been an exciting year with much—almost too much—work. All of us were personally motivated. As Alzheimer relatives, nurses, therapists or researchers, we knew there was a great need for an organization like ours. Our expectations were more than realized. In fact, so much material has come our way that we have had a hard time establishing priorities. For the time being, we have settled on three subcommittees: Public Information, Coordination and Research–all of them now active and well-functioning.

The Public Information Committee has prepared an information folder. Layout, front page and logo was kindly provided by the well-known Danish artist Per Arnoldi. More than 10,000 of these folders have been distributed nation-wide. The first three issues of our quarterly publication *News from the Alzheimer Society* have appeared, containing announcements as well as informative material about dementia and about the many problems associated with care and treatment of afflicted patients.

The Coordination Committee is busy planning and coordinating group activities both locally and nationwide, including the establishment of local chapters in each of our 16 counties. During the past year, the Committee has organized information meetings in ten counties and established six local chapters, all of them headed by an Alzheimer relative. Ten more are in the planning stages. We have set a high priority on these efforts, since the counseling of patients and their relatives is best accomplished by someone familiar with the local conditions.

As yet, we have no budget for research. However, our Research Committee is working a survey of ongoing Alzheimer research with main emphasis on Danish studies, which we hope to publish as a pamphlet later this year. Hopefully this will stimulate the accumulation of funds available for research.

During the past year, our society has had a profusion of inquiries from both therapists and relatives seeking practical advice as well as further information about the dementia syndrome, its causes and how it can be diagnosed and treated. As a result we have expanded our office hours, so we now provide telephone counselling four days a week.

During the coming year, our organization will offer courses for relatives of patients with Alzheimer's disease or similar disorders. The relatives will learn about the symptoms and treatment of patients with Alzheimer disease, about nursing care, financial costs, etc. Furthermore, we intend to arrange seminars for the volunteer counselors and executive members of our local chapters. We also plan to develop a better fundraising program including first of all systemic application for support from private foundations. In Denmark the Government does not provide any funds to patient organizations. Finally, our Public Information Committee continues to develop further information material.

Investigators Study Alzheimer's Disease in Black Americans and Nigerians

A groundbreaking cross-cultural investigation will be the first to study black American and Nigerian older people at risk for Alzheimer's disease (AD). The National Institute on Aging (NIA) will fund the work of researchers at Indiana University and the University of Ibadan, Nigeria.

The study design includes an initial screening interview followed by a clinical evaluation on some of those screened. After one year, interim follow-up examinations will be performed on people identified as having dementing diseases. This will help document the course of disease and determine diagnosis in questionable cases. Two years later, in the study's second phase, they will check for evidence of environmental, genetic or toxic factors that may be a cause of Alzheimer's disease.

Objectives of the study are to determine whether the prevalence and incidence of the disease is lower in the Nigerian than in the black American population. Researchers will collect data on the most common physical signs of Alzheimer's disease in the brain–plaques and tangles. It is suspected that these lesions may differ in size and number in patients with Alzheimer's in Nigeria and in black American patients for reasons that have yet to be determined. Valuable information may be forthcoming from any differences that are observed: if some risk factors can be identified that are common to people in both locations,or if the number of cases in the two locations can be associated with the frequency rates of certain risk factors.

There is accumulating evidence of a genetic basis for a portion of Alzheimer's cases. Still, many researchers presume that environmental factors also must play a role in causing the disease. "All previous studies have been conducted in industrialized countries with highly sophisticated social and health care systems. We hope to see that some risk factors, which are ubiquitous to Westernized societies, will become obvious by comparison with very different societal and cultural environments," said Dr. Hugh Hendrie, principal investigator for the study at Indiana University.

"These studies could significantly speed up the timeframe for research on Alzheimer's disease by quickly identifying exposure to disease pathogens or harmful environmental agents," added Dr. Teresa Sluss-Radebaugh, chief, Dementias of Aging Branch of the Neuroscience and Neuropsychology of Aging Program at NIA. The work conducted by Dr. Hendrie and his colleague in Nigeria, Dr. Benjamin O. Osuntunkon, may yield valuable data like that collected in Nigeria for atherosclerosis, hypertension, and diabetes."

The study goals are to standardize and validate research instruments, assess and compare age-and sex-specific prevalence ratios and incidence rates of the dementing disorders, identify different putative risk factors for dementias and establish a uniform database for subsequent studies of the natural history of dementia.

Dr. Osuntunkon has recently completed a year's sabbatical at the Department of Psychiatry, Indiana University, under a grant from the NIA. He and his coworkers at Indiana University studied dementia in the black community in Indianapolis. They attained a high degree of reliability in the use of an epidemiological screening instrument and neurological evaluations in determining diagnoses of dementia and AD. The screening instrument has been translated into Yoruba, a Nigerian language, and tested successfully in older Ibadan residents for feasibility, consistency and validity.

—Reprinted from News & Features from NIA.

Editor's Note: Global Perspective readers may remember that Dr. Osuntunkon participated in a symposium on Cross-Cultural Studies on Alzheimer's Disease during ADI's 6th International Conference in Mexico City in 1990.

What (In the World) We're Doing...

The Alzheimer Society of Canada in 1992—unveiled its new Strategic Plan. Says President Jeanne Bentley, "During the past year, volunteers and staff across the country have channeled their energy into kindling a vision of a unified Alzheimer Movement. A movement that will meet the needs of all those affected by Alzheimer's disease.

"The goal was to determine our common identity as a movement, while maintaining respect for our regional diversity. As individuals and groups, we have our own identity, but to better serve those who need us, we realized our strength must be found in unity."

The Canadian Society also announced in July that it has awarded 15 Research Grants for a total of $671,000.

In addition, the Society announced that its Project CLEARINGHOUSE is 'going national.' Organized by the Support Services/Education Department at the national office, Project CLEARINGHOUSE is a database that lists information available from Provincial and Local Alzheimer organizations. SEARCHMAGIC software which was supplied to all Provincial offices, allows direct access to the database.

Alzheimer's Association (U.S.A.) 1992—held its first national Education Conference: *Alzheimer Care Strategies: Practical Approaches, Professional Alliances*. The event was designed primarily for professional care providers, over 1,000 persons attended. Proceedings of the Conference have been published.

Alzheimer's Association (Australia) in 1992—Early in March, the Association's National Committee members and State Executive Directors participated in a two day meeting, immediately prior to the Second National Alzheimer's Association Conference held in Adelaide. The committees outlined the Association's national directions for the next year. Special consideration was given to the policies to be included in the National Action Plan on Dementia for the MidTerm Aged Care Review being conducted by the Department of Health, Housing and Community Services.

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Advocacy As Therapy

The following is an excerpt from an address given by Stephen McConnell, PhD, Sr. Vice President for Public Policy, Alzheimer's Association (USA), during the Canadian AGM in April, 1992. (Editor's note: While political systems differ from country to country, there is a significant message here for all ADI members regarding perspectives and the relevance of advocacy).

"My message to you today is simple. It can be summarized in one phrase: "Advocacy as Therapy." I have chosen this theme in part because the Lyon's lecture emphasizes issues of importance to caregivers.

"But, it is also a theme that is central to effective citizenship. Doing advocacy is not only good for others or for public policy, it is also good for you. As they say, "Doing good and doing well."

What is Advocacy?

"The dictionary offers two definitions of advocacy.

"One definition is to "Plead the cause of another." Specifically, to "Plead the cause of another before a tribunal or judicial court." Thus, an attorney is an advocate on behalf of his or her client, pleading the client's case before a judge or jury.

"Elected officials are advocates (or should be) as they plead the case of individual constituents before the legislature or to an agency that is supposed to be providing a designated service.

"As caregivers you are advocates for your loved ones when you represent their interests–plead their case–to a physician, or other service providers. You are their advocate when you explain to a friend why "He acts the way he does." When you plead the case to your children or grandchildren and try to make sense out of this awful disease so they will have compassion and understanding for Grandma.

"The anger, the distant look, the mood swings, the indifference -- you explain that these are caused by the disease. The one afflicted is helpless to defend against it and, you argue, their actions should not be taken as a personal affront. Advocacy—Pleading the cause of another.

"The second definition of advocacy is broader. "Defending or maintaining a cause or proposal."

"One important cause is increased research funding to unlock the mysteries of this disease. Great progress is being made on this front. In the U. S., we have doubled Federal funding in the last two years. We are now spending more than one-quarter billion dollars a year on biomedical research on Alzheimer's.

"As advocates, we defend the cause of research funding so that future generations will not have to experience the pain and suffering that you as caregivers and family members know too well.

"We also advocate for improved long term care services...in the home and in the community, as well as in nursing facilities."

Therapeutic Role of Advocacy

"If advocacy means pleading the case of another and fighting for a cause, what does that have to do with therapy? Therapy for Whom?

"Shelley Fabares, a wonderful American actress who is a member of the Alzheimer's Association's national Board of Directors, sums up what is meant by advocacy as therapy. She talks about the frustration, the pain and sadness associated with each visit with her mother in the nursing home. Her mother shows no signs of recognition. While visible symptoms of torment seem to have subsided, her mother's situation never improves. No matter how long she stays with her...no matter what she says or does...there doesn't seem to be much impact.

"But when Shelley comes to Washington with other family members and advocates to plead her cause before congress, she sees tangible results. Research funding is increased. A new nationwide program is funded to locate missing Alzheimer patients. Her actions produce results! And, that is therapeutic for her as a caregiver. It helps to give her strength and a renewed sense of hope that all of her efforts are not in vain. That she has a purpose. And, that her love for her mother is directed toward a positive goal. Advocacy is therapeutic."

Caregiving is Stressful

"Caregivers for Alzheimer patients are heroes. It is remarkable what they are able to accomplish out of love and devotion. The endless hours. The enormous frustration. The emotional pain. Caregiving is often a lonely task and the stress on the caregiver can be unbearable.

"Ann and her sister Dorothy are 83 year old twins from Los Angeles, California. They came to Washington this year to advocate. Both are gorgeous. One of the twins always has a smile on her face. She seems happy as can be. The other has the look of someone who is tormented by some unseen force.

"Ann, the happy one, has Alzheimer's disease. Her twin sister is the caregiver. As the caregiver, she bears the physical and emotional scars this disease wreaks on caregivers.

"There is strong scientific evidence that caregiving is stressful. It leads to lowered immune functions, more accidents and illness. One half of Alzheimer caregivers suffer from clinical depression. And, the impact does stop at the caregiver.

Orien Reid, a single parent living in Philadelphia, Pennsylvania, describes herself as a member of the so-called "sandwich generation." She is caring for her mother with Alzheimer's and raising two teen-age children. Caregiving has taken a toll on her entire family. Orien has gained weight and now suffers from high blood pressure, all related to the enormous stresses of caregiving.

"Worse yet, her children are suffering. They've been thrust into the role of caregivers when they are still in need of great amounts of care themselves. Orien's son has developed problems in school. Her daughter, once a gregarious and fun-loving child, has become withdrawn. Sadly, the money Orien saved for her daughter's college expenses has been spent on the cost of caring for her mother.

"Orien was forced to place her mother in a nursing home recently because her

After a preparatory training session, Alzheimer's Association Chapter members from across the U.S.A. "march on" to Capitol Hill to visit their legislators, during the Public Policy Forum held annually in the Spring in Washington D. C.

mother had terrorized her son with a coat hanger one day. The family had reached a crisis point and the only solution was to move her mother. The immediacy and constancy of the problem was removed. But, the effects of the disease linger in the Reid household. The scars on Orien and her children will heal slowly, if at all.

"But, Orien Reid chose to act on her pain in the hopes of helping others. She got in touch with our Philadelphia Chapter and is now an active volunteer. Two weeks ago, she came to Washington to tell her story to Congress. She was featured on the evening news. Orien made a difference by pleading her cause. And, it made her feel better. That all she and her family had been through was not in vain. That her story might contribute to a better future. *Her Advocacy was therapeutic."*

The Similarities Between Advocacy and Caregiving

"On the surface, it seems unlikely that an activity as personal and intimate as caregiving would have anything in common with advocacy... which so often seems impersonal and abstract. But, think about it.

"First, the best advocates for a cause are those who know the problem intimately. An elected official will tell you that a personal story is worth a thousand statistics.

"Bill Gold testified before Congress two years ago. Bill had quit Law School to return home to help his father care for Bill's mother, who suffered from Alzheimer's disease. He talked about how he had to sit on her to comb her hair. About how frustrated he felt when his mother repeated the same phrase over and over for days on end. About his own sacrifice, members of Congress remember that story. No amount of data could have the same impact.

"Caregivers know the intimate details of Alzheimer's and can plead the case best. Likewise, when policies and programs are designed, it is the caregivers who are in the best position to fine tune them to ensure the programs will meet people's needs.

"Second, as a caregiver, everything you do is on behalf of another -- the person with Alzheimer's, your loved one. Advocacy by our definition is pleading on behalf of another. It is an easy transition from doing on behalf of to pleading on behalf of...

"Third, caregivers act out of love. There is no stronger motivator. And when advocating out of love...for a husband, for a wife, for humanity in general...it is compelling."

The Therapeutic Aspects of Advocacy

"I've already described one beneficial effect of advocacy...feeling a sense of accomplishment. The example was Shelley Fabares' feeling that her actions as an advocate actually resulted in movement and change.

"Another benefit of advocacy is camaraderie. Some of the best advocacy is done in a group. Like support groups, advocacy teams give moral support and a sense of community, directed toward a common goal. Caregiving is lonely and joining together to advocate brings a wonderful relief to the loneliness.

"A constructive avenue for anger and frustration is a third benefit of advocacy. When anger remains pent up in a person it often results in physical disorders. When a person's anger is channeled outward toward a public policy goal, the cathartic effect of expressing anger and outrage in a constructive way can be beneficial to the caregiver - and, it helps to further our mission."

Forms of Advocacy

"There are many different forms of advocacy. Personal Advocacy, or representing the interests of the person they care for, is the one most familiar to caregivers.

"Legislative advocacy or advocacy before an administrative body, is another form.

"I mentioned the example of Orien Reid, who came to Washington to testify before Congress. That, of course, is a fairly rare occurrence. But the important thing is how it was done. Orien simply told her own story. She didn't try to be an

ARDA South Africa Reaches Out to Neighbors

Recently, we asked ARDA South Africa for an update on activities for the Global Perspective. Following is the report we received.

"There are a few more groups and our two branches are well established. The newsletter now appears six times per year. Membership is presently 470 and enquiries by mail and telephone average 70 per month.

"We have increased our services, too. This year our education programme on dementia has been presented to nurses at hospitals, nursing homes, nursing agencies, training centres and to social workers and occupational therapists. This service is much in demand. We have introduced respite services in a limited way.

"We have also been involved assisting in organizing the establishment of some research projects.

"Contact with families, nursing, social service and medical practitioners in neighboring countries has increased. We help people in Namibia, Zimbabwe, and have assisted some in Swaziland and Botswana in the past. We have helped to establish support services in the two major cities of Zimbabwe, Herare and Bulwayo.

Mark your Calendar!

Alzheimer's Disease International
9th International
Conference & Annual Meeting
•
Toronto, Ontario,
CANADA
September 20-24, 1993

What (In the World)—Continued

Alzheimer's Society of Ireland in 1992—held its Alzheimer Awareness Week from July 6–13. One item of support the Society is very anxious to make available to Carers is some form of respite in the home in order to enable the Carer to take a few hours off. The Society is studying ways this can be accomplished through existing national resources.

ADARDS (New Zealand) in 1992—is confidant in its long range planning. In May the Council members and Management Committee worked together to establish goals for the organisation for the next five years, and to set objectives for the year ahead. This process has helped the Society to maintain direction and to monitor its progress.

Three candidates for ADI membership (Brazil, Israel and Japan) will present their credentials at the 8th Annual Meeting in Brussels.

Advocacy as Therapy—Continued

expert about policy. She didn't cite numbers or facts. She merely described her family's experience in dealing with Alzheimer's.

"Letter writing is an easy and enjoyable form of advocacy. Some people hold "house parties" where they invite neighbors and friends for tea and then as a group they write letters in support of the Alzheimer cause. Simple...fun...personal ...therapeutic.

"Meeting with legislators or the Minister of Health, or a local agency head is a form of advocacy available to everyone. Scheduling a meeting, either individually or as a group, to discuss Alzheimer issues is very effective.

"Henry Alisa from Wilmington, Delaware, is a caregiver for his mother. He had no experience with public policy advocacy until he visited with his senators and member of Congress. It turns out that his mother had worked on the campaign of Senator Biden, one of Henry's Senators. This, plus Henry's straightforward, honest and sincere style, led to a friendly relationship with the Senator that ensures Henry's messages will be heard. Henry is now one of the most dedicated advocates we have.

"Support Group Advocacy is a very powerful way to get a message to our leaders. Support groups often see their role, like caregivers, as personal and focussed inward. Asking support group participants to write a letter to the legislature is an excellent way to do advocacy and to reap its therapeutic benefits. Focus the frustration outward.

"Ruth Rabyne from Chicago, Illinois, has drawn on the many talents of support group participants. Recently, she arranged for one participant to testify at a hearing on long term care held by members of the U. S. Congress in Chicago. This person's personal story of tragedy and pleading the case, was very effective in convincing the visiting legislators that something must be done. Yesterday, those legislators who attended that Hearing and who've heard the stories in other settings, introduced legislation to help address the long term care crisis in the United States."

'Caregiver for a Day'

"With the many competing demands on Legislators, it is important to make them intimately familiar with the ravages of this disease. One way to do that is by inviting them to be a "caregiver for a day." It works like this:

- Elected representative is invited to a home to help provide care to an Alzheimer patient.
- Then, the representative visits a day care center and helps with social activities for residents
- Later, s/he may help deliver "meals on wheels to people confined to their homes"
- The media is invited to go with the representative.

"This is what happened with more than 75 Senators and members of Congress during the last two years. After their 'caregiver for a day' experiences, they could not go back to Congress and vote on an issue related to Alzheimer's disease without recalling the experience they'd had as a caregiver.

"There are also side benefits to the 'caregiver for a day' event. It helps get media coverage for our issues (as well as for the elected representatives). And, it gives visibility for programs you might want to promote.

"Broadcast Media and Press. These contacts are very important. Getting the media to cover a story in your community

The Physical Environment as a Therapeutic Resource in Settings for People with Dementia

The physical environment is a potentially significant, but often overlooked resource, in efforts to enhance the quality of life of older persons. Recently, research and design efforts have examined environments for older adults with cognitive impairments, particularly those resulting from dementia (Cohen and Weisman, 1991; Cohen and Day, in press). Based upon this work, this article will present some of the key concepts in this context, and a set of principles for design.

Our approach to the task of developing research-based information for design has been three-fold. First, we have endeavored to build upon both clinical experience and empirical research. This has involved review of practice-oriented as well as scholarly publications, extended interviews with both care providers and researchers, visits to existing facilities, and analysis of relevant codes and standards. Secondly, we have synthesized our findings into a set of *Principles for Planning and Design*; these principles have clearly specified objectives, are open-ended rather than prescriptive, and are amenable to testing and validation. Third, these principles are organized within the framework of facility development; in moving from preparation, to planning, programming, design, construction, occupancy and evaluation, all participants in the process are able to learn from one another as well as from available research-based guidance. Finally, the implementation and integration of these principles is explored in a number of *illustrative designs* such as Day/Respite Care and Long Term Care examples which demonstrate the application of design principles in typical projects.

The final set of 18 principles are presented in *Holding on to Home* (Cohen & Weisman, 1991). Oriented toward social service and health care professionals as well as environmental planners and designers, *Holding on to Home* endeavors to provide all of these groups with an appreciation of the therapeutic potential of the physical environment in the care of people with dementia. While this brief article can provide only an introduction to these issues, understanding of the relationship between architecture and Alzheimer's disease depends upon three fundamental premises.

First, it is essential to recognize that the role of the architectural environment need and should not be limited to the mere provision of physical shelter. Thoughtfully designed architectural environments

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helps others not in your group to become allies in your advocacy. This can be done by inviting the press to write about someone or about something you are doing. Another way is to visit the editorial board of your local newspaper and to advocate with them."

Summary of Forms of Advocacy

"To summarize, legislative advocacy takes many forms—letter writing, personal visits, support groups actions, caregiver for a day and media. All are effective. All are therapeutic. And all draw on your personal experiences as caregivers."

Key Elements of Advocacy

For those of you who are already familiar with the basics of advocacy and who would like to become active in helping others advocate, there are several tips to keep in mind. Here are some of the key elements of effective advocacy.

"Keep it personal. We have already discussed the power of a personal story. But, its importance can't be stressed enough.

"Know Your Subject. Know what you are asking for when you meet with an elected official. Have your arguments well prepared.

"Keep the message simple. Some people use the 3 X 5 rule. If it fits on a 3 by 5 inch card, it is probably about right. Anything longer is probably too much.

"Know your Audience. Talk to your legislator's or ministry staff in advance. If your legislator has a particular interest, be sure to inform yourself about it, and make use of it if you can. If he or she is an Alzheimer family member, be sure you know that ahead of time. If he or she is on a key legislative committee, frame your message accordingly. Meet your audience where they are. You will have a much better chance of reaching them.

"Give to Get. Be prepared to give something in exchange for help. We're not talking money or bribes. But, if you can invite your legislator to your group meeting and give him or her an audience, that is a good way to encourage him or her to come address your issues. Media coverage is also a good thing to give in exchange, which is why the caregiver for a day events are successful. Self-interest is a powerful tool. Be sure you make use of it.

"Form Coalitions. Other groups who share your interests can be important allies in your struggle. Many of those concerned about aging and health issues are natural allies. Be sure to link up with them to increase the volume and power of your message."

Conclusion

"As caregivers, we have enormous power. Our experiences, when communicated to those in positions of authority, carry great weight. That alone should motivate us to act. To hit the streets and become advocates!

"But, that isn't enough for many people because advocacy is a foreign experience. It seems so formidable and technical. So specialized and even frightening,

"That's where the therapy message is so important. That's when we as caregivers begin to realize that our advocacy is good for us. That advocacy is therapeutic. That it gets us out of our loneliness and gives us a tool to make change, and a means to feel that we've accomplished something. That's a motivator.

"The next time that feeling of hopelessness wells up, or the frustration level hits new heights...write a letter. Send a telegram. Call a friend and go visit an official or their staff. Send a letter to the editor,

"Be an advocate. It might surprise you how good it feels."

The Physical Environment as a Therapeutic Resource

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represent potentially valuable, albeit typically underutilized, therapeutic resources in the care of people with dementia. Indeed it has been argued that many of the behaviors attributed to Alzheimer's disease are, in part, a consequence of counter-therapeutic settings. There is empirical and theoretical support to suggest that even modest modification of traditional room and unit layouts, along with complementary modifications in the organizational environment, can moderate the inevitable declines expected over time in the behavior of people with dementia.

Secondly, it must be recognized that the physical settings occupied by people with dementia do not exist in isolation; rather, they are integral parts of a larger, complex system and must operate in concert with the social and organizational dimensions of this larger system. Thus, *physical* environments for people with dementia must be considered in the context of *social*, *behavioral*, and *organizational* variables.

Finally, there is great value in recognizing the *residential* qualities of environments for people with dementia. Many such facilities, while well-intentioned, do not, as a consequence of their medical or institutional characteristics, serve the best interests of people with dementia. All therapeutic settings should retain the positive attributes of home to the greatest extent possible.

SELECTED DESIGN PRINCIPLES

Eliminating Environmental Barriers. Physical and cognitive impairments with dementia often make movement through and use of the environment difficult. It is critically important to eliminate these barriers to negotiability in environments for people with dementia. In addition to traditional solutions such as ramps or handrails, environmental interventions may include clear and consistent information and easy-to-operate handles and controls.

Things from the Past. Familiar artifacts, activities, and environments can provide valuable associations with the past for people with dementia, and can stimulate opportunities for social interaction and meaningful activity. Rather than being limited to a simple "rummage box," the total environment may potentially be used to trigger reminiscence.

Sensory stimulation without Stress. Levels of sensory and social stimulation in environments for people with dementia should not differ dramatically from those encountered in domestic environments. Both sensory deprivation and overstimulation are conditions to be avoided. The physical and the organizational environments can be designed to regulate stimulation, providing interest and challenge without becoming overwhelming. Opportunities should be provided for increasing or reducing levels of stimulation to respond to changing needs and tolerance levels over the course of a day.

Opportunities for Meaningful Wandering. Wandering is a relatively common behavior among people with dementia. Too often in the past it has been viewed only as a problem, and resulted in the use of chemical and physical restraints. A far more positive approach is to view wandering as an opportunity for meaningful activity. Both physical and organizational environments should be supportive of such activity, providing appropriate settings with secure and well-defined paths for wandering.

Public to Private Realms. People with dementia should be able to select from among a variety of spaces falling at distinct points along a continuum of public to private realms. Such a continuum, created through both architectural and administrative means, facilitates resident control of sensory and social stimulation, and may reduce perceived intrusion of individual personal space.

Principles for Planning and Design

The design of environments for people with dementia must take into account their special and specific needs, the distinct goals of their caregivers (family members and staff care providers) and the organizational environment. The design principles developed in *Holding on to Home* address critical issues (e.g., wandering behavior) and provide directions for solutions (e.g., meaningful wandering path) responsive to the needs of residents and caregivers. Appropriate solutions will vary with the nature of the population to be served and the specific environment under investigation. The design principles offer suggestions that cover the entire design process, from general planning principles (e.g., suggestions for tapping local resources), to building organization (e.g., recommendations for small groups of residents), to specific activity areas (e.g., domestic kitchens).

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Editor's Note: We regret that for space limitations an Illustrative Design for Day and Respite Care Centers was omitted. The design shows 1. An area for intimate dining and domestic kitchen to reinstate meaningful social roles; 2. A Wandering Path, to contribute to reduced restraints and ensure that wandering is a positive experience; 3. Accessible toilet areas, to increase the potential for control of incontinence and improve self-image; 4. Beauty shop, to introduce a familiar, community-based activity; 5. An area for unobtrusive observation to reduce institutional intervention, allowing greater freedom of movement; and, 6. Positive outdoor space, a secure courtyard with differentiated activity areas that enlarge the scope of daily experiences. The omitted illustration is one of several designs provided in "Holding on to Home."

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919 N. Michigan Avenue, Chicago, Illinois 60611.
Tel: (312) 335-5777 - Fax: (312) 335-1110.

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