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ABSTRACT

This document contains two brief bibliographies of peer-reviewed literature, with abstracts, on dementia and Alzheimer's disease in the elderly, one written for the educator and the other for the consumer. They are two of 12 bibliographies on aging prepared by the National Agricultural Library for its "Pathfinders" series of publications. Topics covered by the other 10 bibliographies include aging parents, adult children, family caregiving, family support networks, grandparenting, humor in later life, intergenerational relationships, living arrangements in later life, pets and the elderly, and sibling relationships in adulthood. The bibliography on dementia and Alzheimer's disease in the elderly written for educators contains citations for 13 books, 4 brochures, 2 Alzheimer's journals, 7 journal special editions on dementja, and 14 videos. It concludes with a list of organizations that readers may contact for further assistance. The bibliography on dementia and Alzheimer's disease in the elderly written for the consumer contains citations for 3 brochures on Alzheimer's disease, 6 journal special editions on dementia, and 11 books and concludes with a list of organizations for further assistance. (NB)

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National Agricultural Library

From The Family Information Center

FEBRUARY 1990

DEMENTIA AND ALZHZIMER'S DISEASE IN THE ELDERLY

Prepared by Billie H. Frazier* and Gle.n I. Kirkland**

This PATHFINDER has been prepared to help educators access information on Alzheimer's disease and dementia in general.

EDUCATOR

BOOKS

Adult Day Care For Persons with Alzheimer's Disease and Related Disorders: A Training Manual for Staff, Gloria Levine and Joan Scharf. Cleveland, OH: Menorah Park Center for the Aging, 1987.

Background information and useful suggestions for those involved with care of the demented in an adult day care center are provided. This book parallels a 22 minute video presentation on the same subject.

A Better Life: Helping Family Members, Volunteers and Staff Improve the Quality of Life of Nursing Home Residents Suffering from Alzheimer's Disease and Related Disorders, Dorothy H. Coons, Lena Metzelar, Anne Robinson, and Beth Spencer. Columbus, OH: The Source for Nursing Home Literature, 1986.

This book resulted from a national study of caregiving families. Among other things, it describes three examples of an exciting approach to caring for people with dementia in a nursing home setting.

This PATHFINDER lists significant resources that are judged to be authoritative, accurate, readable, and available. Opinions expressed in the publication do not reflect views of the United States Department of Agriculture.



Care of Alzheimer's Patients: A Manual for Nursing Home Staff, Lisa P. Gwyther. Washington, D.C.: American Health Care Association/Chicago, Il: Alzheimer's Association, 1985.

A brief review of some important considerations about Alzheimer's patients is provided. Methods of dealing with specific behavioral problems are suggested. Copies may be obtained from either organization.

Design for Dementia: Planning Environments for the Elderly and the Confused, Margaret P. Calkins. Owings Mills, MD: National Health Publishing, 1988.

Many simple techniques for providing an appropriate environment for persons with dementia are given in this book.

Handbook of Geriatric Assessment, Joseph J. Gallo, William Reichel, and Lillian Andersen. Rockville, MD: Aspen Publishers, Inc., 1988.

The authors provide a set of assessment tools for the evaluation of mental, functional, social, economic, physical, maintenance, and geriatric status of individuals.

Losing A Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias, Office of Technology Assessment. (OTA-BA-323). Washington, D.C.: Government Printing Office, 1987.

Prepared at the request of several committees of Congress, this report discusses the medical, social, political, and financial aspects of dementia in the elderly and assesses the impact of these diseases on the Nation.

The Myth of Senility: The Truth About the Brain and Aging, Robin Marantz Henig. Washington, D.C.: American Association of Retired Persons, Revised 1985.

The author explains what is and is not known about memory, brain changes with age, intelligence, Alzheimer's disease, senility, and the environment as it affects the brain.



Psychiatric Treatment of Alzheimer's Disease, Group for the Advancement of Psychiatry. New York, NY: Brunner/Mazel Publishers, 1988.

Diagnosis and treatment of dementia is covered. A set of case examples and several rating scales are included.

Social Work and Alzheimer's Disease: Practical Issues with Victims and Their Families, Rose Dobrof (ed.). New York, NY: The Haworth Press, 1986.

A series of papers on a variety of topics related to Alzheimer's Disease is presented in this document.

The 36 Hour Day: A Family Guide for Persons with Alzheimer's Disease, Related Dementing Illnesses and Memory Loss in Later Life, Nancy L. Mace and Peter V. Rabins. Baltimore, MD: The Johns Hopkins University Press, 1981.

This remains one of the best known, most comprehensive publications available on the topic. It is authoritative, relevant, and available in Spanish and seven other languages. More than half a million copies have been sold.

Treatments for the Alzheimer's Patient, Lissy F. Jarvik and Carol Hunter Winograd. New York, NY: Springer Publishing Company, 1988.

Clinical care, family and community interventions, policy, and research are topics of the four main sections of this book. Individual chapters are prepared by specialists in their field.

Treatment Development Strategies for Alzheimer's Disease, Thomas Crook, Raymond Bartus, Steven Ferris, and Samuel Gershon.
Madison, WI: Mark Powley Associates, Inc., 1986.

This report provides information on the status of research in a number of areas and a review of on-going federal research programs.

3

Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses. Anne Robinson, Beth Spencer, and Laurie White. Ypsilanti, MI: Eastern Michigan University, Geriatric Education Center of Michigan, 1989.

The main focus is on specific behavioral challenges of the caregiver. It is an 80 page document with easy to read print.

BROCHURES

Coping and Caring: Living with Alzheimer's, Charles Leroux. Washington, D.C.: American Association of Retired Persons, 1986.

Produced as part of AARP's Health U.S. Campaign, and in cooperation with Alzheimer's Organization (ADRDA, Inc.), this brochure provides consumers with information about important health care issues and also specific answers about Alzheimer's disease.

Dementia and Alzheimer's Disease in the Elderly. Billie H. Frazier and Glenn I. Kirkland. College Park, MD: The University of Maryland Cooperative Extension Service Bulletin 335, 1988-1989.

The authors include sections on: dementia; Alzheimer's disease; caregiving at home; legal and financial issues; community resources; and nursing home care.

Long Term Care: A Dollar and Sense Guide, Susan Polniaszek and David Lewis. United Seniors Health Cooperative, 1334 G Street, N.W., Suite #500 Washington, D.C. 20005, 1988.

Major questions raised about long term care are answered in this guide as well as information regarding long term care services and alternative means of payment.

Selected Books on Alzheimer's Disease and Related Topics: An Annotated Bibliography, Glenn I. Kirkland. Baltimore, MD: Alzheimer's Association, 1989.

This is a packet of brief, informal reviews of selected publications of interest to the Alzheimer's community. Reviews were prepared for publication in the newsletter of the local Alzheimer's Association chapter.



ALEMBIMER'S JOURNALS

Alzheimer Disease and Associated Disorders-An International Journal. Western Geriatric Research Institute, P.O. Box 368, Lawrence, Kansas 66044.

Published quarterly, this journal is an international medium for publication of authoritative and original scientific contributions with primary emphasis on research related to dementia.

American Journal of Alzheimer's Care and Related Disorders and Research. Prime National Publishing Corporation, 470 Boston Post Road, Weston, Massachusetts 02193.

Articles of general interest and research abstracts are included in this bi-monthly journal.

SPECIAL EDITIONS ON DEMENTIA

Generations, VII(1), Fall 1982. The Journal of the Western Gerontological Society, Western Gerontological Society, 833 Market Street, Room 516, San Francisco, CA 94103.

This edition is devoted to Alzheimer's Disease and Related Disorders and includes topics on: diagnosis; legal views; research; genetics; care; depression; community perspectives; self-help groups; and other pertinent issues.

Generations, IX(2), Winter 1984. The Journal of the Western Gerontological Society, Western Gerontology Society, 833 Market Street, Room 516, San Francisco, CA 94103

An "Update on Alzheimer's" is the theme of this publication. Topics range from diagnosis to research to aluminum to poetry. Day care, sleep, and medical imaging are also covered.

Alzheimer Disease and Associated Disorders-An International Journal, 1(1), 1987.

This special edition contains Dr. Alois Alzheimer's original case report which he presented at the meeting of Southwest German Psychiatrists on November 3, 1906.



Pride Institute Journal of Long Term Home Health Care, 3(4), Fall 1984.

Focusing on "Alzheimer's Disease at Home: Helping the Victims and the Caregivers", this publications includes special reports and book reviews prepared by well known authorities.

<u>Provider</u>, 12(5), May 1986. American Health Care Association. Washington, DC, 1200 15th St. N.W. 20005.

This edition contains articles by several nationally known, recognized authorities. The materials are written for health care providers.

Journal of Gerontological Nursing, Slack Inc., Thorofare, NJ 08086 "Alzheimer's Disease: An In-Depth Report 1982-1983".

This is the second annual issue devoted to the theme of Alzheimer's. A wide range of topics are included.

<u>Journal of Gerontological Social Work</u>, The Haworth Press, Inc., New York, NY, "Social Work and Alzheimer's Disease - Practical Issues With Victims and Their Families", 9(2), Winter 1985/86.

Contents include discussions on special nursing home units, social work groups, working with families, educational/support groups, adult day care, and family respite. Book reviews are provided.

VIDEOS FOR THE EDUCATOR

The following ten videos are available from:

Video Services, Department of Physical Therapy University of Maryland School of Medicine 32 South Greene Street Baltimore, MD 21201 (301) 328-5497 or (301) 328-7720

Living with Grace, an award winning video presents a series of vignettes taken during five months in the life of Grace, who is afflicted with Alzheimer's Disease. Focus is on the husband's efforts so their life can continue with dignity and meaning. It was videotaped six years after the initial diagnosis (30 minutes).



2. Caregiving with Grace was videotaped ten years after the initial diagnosis. It documents daily care provided by Grace's husband and a foster home caregiver. Both discuss practical and emotional solutions for caregiving with Grace (35 minutes).

These two programs illustrate changes that occur in an Alzheimer's victim over a ten year period.

- Perspectives on Grace: Medical Implications is designed to be used in conjunction with Living with Grace and Caregiving with Grace. A noted physician comments on medical and social implications of her condition and their impact on the family (20 minutes).
- Perspectives on Grace: Nursing Care Implications presents an overview of behavioral and emotional symptoms associated with various stages of Alzheimer's disease and dementing illnesses. Commentary is based on the case presentation in the documentaries, Living with Grace and Caregiving with Grace. Specific caregiving strategies are addressed (20 minutes).
- Nursing Care for Elderly Dementia Patients is a presentation on the cognitive and behavioral manifestations of dementia syndromes. The emphasis is on the use of the nursing process to develop, implement, and evaluate a comprehensive patient care plan (25 minutes).
- 6. <u>Caregiver Stress</u> includes strategies for stress management, stress reduction, coping with caregiving roles, and improving the general and the mental health of the caregiver. The video is directed toward home caregivers (25 minutes).
- 7. <u>Depression and Dementia</u> presents a discussion on depression in elderly dementia patients who are residents in longterm care facilities. The physician defines depression, explains how to identify it, and suggests intervention, management, and treatment (20 minutes).



- What is Dementia? provides discussion on Alzheimer's disease and related dementing illnesses. A physician provides the basic overview of symptoms and describes how a diagnosis is made. This tape serves as an introduction to Alzheimer's disease for health professionals, volunteers and family caregivers (16 minutes).
- Solutions for Today examines medical and psychosocial interventions and addresses what can be done for dementia patients and their families. A physician provides an overview of practical principles for responsive caregiving, and exploring challenges and rewards (20 minutes).
- 10. Medication and Dementia describes the use, precautions, and side effects of medications used with patients having Alzheimer's disease and related dementing illnesses (20 minutes).

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The following video is available from:

Oregon Health Sciences University School of Nursing 3181 S.W. Sam Jackson Park Road Portland, OR 97201 (503) 279-7709

Working With the Confused Elderly presents specific verbal and nonverbal caregiving techniques designed to enhance coping skills such as dealing with problems of wandering, disorientation, and paranoia. (29 minutes)

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The following videos are available from:

Alzheimer's Disease Project
The University of Michigan
300 N. Ingalls Building, Room 952 N.E.
Ann Arbor MI 48109-2007
(513) 764-8298

Terra Nova films, Inc. 9848 South Winchester Avenue Chicago, IL 60643 (312) 881-8491

- 1. Wesley Hall: A Special Life documents a cooperative project between the Institute of Gerontology of the University of Michigan and a nursing home to improve the quality of life of Alzheimer's disease victims (28 minutes).
- Helping People With Dementia and Activities of Daily Living demonstrates the use of task breakdown for working with Alzheimer's patients. Examples of activities included are: brushing the teeth; setting the table; and getting dressed (Slides on video; 22 minutes).
- Designing the Physical Environment For Persons With Dementia presents environmental modifications that can be made to deal with disorientation, spatial problems, and general sensory loss. It was developed in conjunction with the Wesley Hall Pilot Project (Slides on Video; 20 minutes).

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For information on a lending library of 400 training videos and over 300 pieces of printed material related to dementia and Alzheimer's Disease, contact:

The Hillhaven Foundation Dept. TJ 1148 Broadway Plaza Caller Service 2264 Takoma, WA 98401-2264 (206) 756-4831

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ORGANISATIONS

Alzheimer's Association (A.D.R.D.A., Inc.) 70 E. Lake Street Chicago, IL 60601-5997 1-800-621-0379

Alzheimer's Society of Canada 1320 Yong Street STE 302 Toronto, ONT M4T 1X2 416-925-3552

American Association of Retired Persons 1909 K. Street, NW Washington, D.C. 20049 (202) 872-4700

American Parkinson's Disease Information and Referral Association The Johns Hopkins Hospital, 1-130 Meyer 600 North Wolfe Street Baltimore, MD 212205 (301) 955-8795

Family Survival Project 425 Bush Street Suite 500 San Francisco, CA 94109 (415) 434-3388

The French Foundation for Alzheimer Research 11620 Wilshire Boulevard Los Angeles, CA 90025 (213) 470-5462

Huntington Disease Society of America 140 West 22nd Street New York, NY 20011-2420 (212) 242-1968

National Council on Aging, Inc. 600 Maryland Avenue, SW Washington, D.C. 20020 (202) 479-1200



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9000 Rockville Pike, Building 31
Bethesda, MD 20205
(301) 496-1752

National Library of Medicine 8600 Rockville Pike Bethesda, MD 20894 (301) 496-6095

CONTACT FOR ASSISTANCE

Toll Free HOTLINE 1-800-621-0379

Center on aging at a university

County Cooperative Extension Service (under county government in telephone book)

Dementia clinics

Local, county, area, or state office on aging

Local Alzheimer's Association chapter

Medical schools

This PATHFINDER resulted from the authors' research at the National Agricultural Library during the summer and fall of 1989 during which relevant educational materials were reviewed and annotated. It is authored by:

- Billie H. Frazier, Ph.D., Certified Family Life Educator, Associate Professor, Human Development Specialist, The University of Maryland Cooperative Extension Service, College Park, Maryland
- Glenn I. Kirkland, M.S., founding president of the Alsheimer's Disease and Related Disorders Association Chapter of Baltimore/Central Maryland; member of Maryland Governor's Task Force on Alsheimer's Disease and Related Disorders, participant in "Living With Grace" and "Caregiving With Grace"; recipient of 1989 "Geri" Award, Maryland Senior Citisens Hall of Fame



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- Reviewer: Dr. Judith L. Warren, Gerontology Specialist, Texas A&M University, Texas Agricultural Extension Service, College Station, Texas
- Technical Support: Kathleen C. Hayes and Sandra L. Facinoli, Technical Information Specialists, National Agricultural Library and United States Department of Agriculture
- For questions or comments: Contact Billie H. Frazier, Room 2309 Computer and Space Sciences Building, University of Maryland, College Park, Maryland 20742-2451, Telephone: (301) 454-3602.

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DEFENTIA AND ALZHEIMER'S DISEASE IN THE ELDERLY
Prepared by Billie H. Frazier* and Glenn I. Kirkland**

This PATHFINDER has been prepared to help consumers better understand dementia and Alzheimer's disease in the elderly, coping techniques, resources, and to access additional information on the topics.

CONSUMER

BROCHURES

Coping and Caring: Living with Alzheimer's, Charles Leroux. Washington, D.C.: American Association of Retired Persons, 1986.

Produced as part of the American Association of Retired Person's (AARP) Health U.S. Campaign, and in cooperation with Alzheimer's Association (ADRDA, Inc.), this brochure provides consumers with information about important health care issues and also specific answers about Alzheimer's disease.

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SPECIAL EDITIONS ON DEMENTIA

1. Alzheimer Disease and Associated Disorders-An International Journal, 1(1), 1987.

This special edition contains Dr. Alois Alzheimer's original case report which he presented at the meeting of Southwest German Psychiatrists on November 3, 1906.

2. <u>Provider for Long Term Care Professionals</u>, American Health Care Association, 12(5), May 1986.

This edition covers some of the best current thinking and actions. Nationally known authors make significant contributions.

3. <u>Generations</u>, Miriam K. Aronson and Robert Katzman (eds.). VII(1), Fall 1982.

This edition is devoted to Alzheimer's Disease and Related Disorders. Topics covered include diagnosis, legal views, research, genetics, care, depression, community perspectives, self-lalp groups and other pertinent issues.

4. Generations, Judy MacLean (ed.). IX(2), Winter 1984.

An Update on Alzheimer's is the theme of this publication. Topics range from diagnosis to research to aluminum to poetry. Day care, sleep and medical imaging are also covered.



5. <u>Journal of Gerontological Nursing</u>, Alzheimer's Disease:
An In-Depth Report. Slack, Inc. Thorofare, NJ, 1982-1983.

This is the second annual issue on the theme of the disease/killer, Alzheimer's.

6. "Long-Term Care: A Dollar and Sense Guide," Susan Polniaszek and David Lewis. United Seniors Health Cooperative, 1334 G Street, N.W., Suite #500 Washington, D.C. 20005, 1988.

Major questions raised about long term care are answered in this guide as well as information regarding long term care services and alternative means of payment.

BOOKS

Also My Journey: A Personal Story of Alzheimer's, Marguerite Henry Atkins. Wilton, CT: Morehouse-Barlow, 1985.

This is an emotion-filled account of how one woman dealt with her husband's mental and physical deterioration from Alzheimer's disease.

Alzheimer's Disease: A Guide for Families. Lenore S. Powell and Katie Courtice. Reading, MA: Addison-Wesley Publishing Company, 1983.

The authors discuss with the gamut of emotional pressures on caregivers and illustrate points from real life situations.

Alzheimer's Disease: The Silent Epidemic, Julia Frank. Minneapolis, MN: Lehner Publications Company, 1985.

This is an easy to read publication and would be most appropriate for young adults and teenagers.



Caring: A Family Guide to Managing The Alzheimer's Patient At Home, Fredericka Tanner and Sharon Shaw. New York, New York: New York City, Alzheimer's Resource Center, July 1985.

A comprehensive 100 page, illustrated manual that includes detailed step by step guidelines for managing the Alzheimer's patient at home through the various stages of the progressive disease. To obtain a copy, write to: Fund for Aging Services, New York City Resource Center, 280 Broadway, Room 214, New York, New York, 10007.

Daughters of the Elderly: Building Partnerships in Caregiving, Jane Norris, (ed.). Bloomington, IN: Indiana University Press, 1988.

Almost 5 million of the 30 million persons over 65 are cared for chiefly by women family members. This book offers supportive information and experiences. Comments and advice are provided from professionals to assist caregivers sort out the physical, mental, and emotional aspects of aging and caregiving.

Getting Through: Communicating When Someone You Care For Has Alzheimer's Disease, Elizabeth Ostuni and Mary Jo Santo Pietro. Princeton Junction, NY: The Speech Bin, 1986.

Four major components of communication discussed in this book are the: (1) person with dementia, (2) caregiver,

(3) communication between patient and caregiver, and

(4) communication environment.

Grandpa Doesn't Know It's Me, Donna Guthrie. New York, NY: Human Sciences Press, Inc., 1986.

This book deals with potential concerns of the young child who has a close relative with Alzheimer's Disease. It answers such questions as: What is wrong? Did I do anything to cause it? Will I get it? Why did it happen? To help children better understand the difficult situation with their relative, this book can open dialogue between parent and child.

How to Care for Your Parents: A Handbook for Adult Children, Nora Jean Levin. Washington, DC: Storm King Press, 1986.

This paperback lists and discusses twenty eight specific things a person needs to consider when caring for a functionally-disabled elder.

Managing Grief and Bereavement: A Guide for Families of Memory-Impaired Adults and Other Chronically Ill Persons, Edna L. Ballard. Durham, NC: Duke University Medical Center, 1989.

Anticipatory grief and realized grief are discussed in this book. It includes ways of dealing with bereavement and is written to support family caregivers.

The 36 Hour Day: A Family Guide for Persons with Alzheimer's Disease, Related Dementing Illnesses and Memory Loss in Later Life, Nancy L. Mace and Peter V. Rabins. Baltimore, MD: The Johns Hopkins University Press, 1981.

This remains one of the most comprehensive publications available on the topic. It is authoritative, relevant and has been translated into Spanish and seven other languages.

Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses, Anne Robinson, Beth Spencer, and Laurie White. Ypsilanti, MI: Eastern Michigan University, Geriatric Education Center of Michigan, 1989.

The main focus is on how the caregiver can cope with specific behavioral challenges brought on by caregiving responsibilities. This is an 80 page document with easy to read print.

ORGANIZATIONS

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The French Foundation for Alzheimer Research 11620 Wilshire Boulevard Los Angeles, CA 90025 (213) 470-5462

National Council on Aging, Inc. 600 Maryland Avenue, SW Washington, D.C. 20020 (202) 479-1200

National Institutes of Health Public Health Service U.S. Department of Health and Human Services 9000 Rockville Pike, Bldg 31 Bethesda, MD 20205 (301) 496-1752

National Library of Medicine 8600 Rockville Pike Bethesda, MD 20894 (301) 496-6095

CONTACT FOR ASSISTANCE

Toll Free HOTLINE 1-200-621-0379

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- ** Gleng I. Kirkland, M.S., founding president of the Alzheimer's Disease and Related Disorders Association Chapter of Baltimore/Central Maryland; author; participant in "Living With Grace" and "Caregiving With Grace"; and recipient of 1989 "Geri" Award, Maryland Senior Citizens Hall of Fame
- Reviewer: Dr. Judith L. Warren, Gerontology Specialist, Texas A&M University, Texas Agricultural Extension Service, College Station, Texas
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