

April 13, 1999

JOINT FINANCE COMMITTEE HEARING---STEVENS POINT, WI

Thank you Representative Gard and Senator Burke for the opportunity to speak to this committee today. My name is Reginald R. Westphal and I practice oral and maxillofacial surgery in Stevens Point at 520 Vincent Street. I am an independent solo practitioner with a staff of six and a half full-time employees. Thank you for bringing this hearing to Stevens Point because it greatly facilitates the process of government and demonstrates to us your concern and consideration.

I am here to speak in favor of the Governor's budget bill relating to the proposed changes for the Medicaid program; specifically the dental Medicaid program. I am pleased with the proposed budget increases for the dental Medicaid program, but I hope for much more. It is my sincere hope that we can all agree that this budget cycle is the time to do what is necessary and right for the children, the young people, and the elderly who are in great need of basic dental services in Wisconsin. I know we can do this!

Step one. We need to solve the paperwork problems which are slowly, but surely, destroying the dental Medicaid program. I am positive that we **can create a reimbursement system that is just as "user friendly" as any other dental reimbursement plan** operating within this state under the supervision of the State Insurance Commissioner. This will tremendously benefit the recipients of care. Delays of care will be reduced or eliminated. This will promote utilization. An efficient, responsive pre-determination system will ensure that the designated benefits you have legislated will, in fact, be provided on a daily basis to the needy. I can assure you that by creating a "user friendly" system we will automatically ensure increased provider participation. The paperwork problem, I believe, is the number one issue preventing delivery of dental Medicaid benefits; all other problems pale in light of this major roadblock. When we fix the reimbursement system the dental Medicaid program will recover and achieve the success we all are hoping for today. Why do I say this? The dentists of this state voluntarily donate tens of thousands of dollars in care to the needy each year without any compensation because it is a "user friendly" method of care provision. Yes, the current low reimbursement level is an important element of the dental Medicaid dilemma but, I submit to you, that the methods of pre-determination and reimbursement are just as important to us as providers of care. There is nothing that can overcome this "user friendly" roadblock except removal. We can do this!

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Step two. The governor's budget increase is an essential "step in the right direction", and we applaud him for this. In 1981 25 million dollars was spent on dental Medicaid reimbursement. This year the state has projected only 9 million dollars in dental Medicaid expenditures! Currently only about 7 tenths of one percent of the Medicaid budget is spent on dental care. For our dental Medicaid program to achieve its intended goals this percentage must increase. This percentage must increase in order to provide the amount of care, and level of care, required in our great state. Continuing to increase this percentage each budget cycle will, over the long haul, provide increased access to care because it will encourage more dentists to participate as providers. You ask, "Why?" Let me explain. The overhead cost of most dental practices in this state is about 70%---nearly double that of the average medical practice. Compare this to a dental Medicaid reimbursement percentage of 55% in Portage County, according to the latest figures from the BHCF. Statewide the dental reimbursement figure is about 53%. Dentistry desperately needs your help to close this **critical "operational expense gap"** so dental providers can maintain fiscal responsibility within their respective practices while providing Medicaid dental services to those most in need of them. We need to shoot for a reimbursement level of 85% of "current" filed fees; a reimbursement level last used in 1981!

Step three. We need to create now an ongoing **long term DENTAL MEDICAID TASK FORCE** that will assist the legislature in implementing Steps One and Two. We, as a profession, stand ready to assist you and the legislature in this endeavor.

Step four. Let us not forget the future availability of dental practitioners for our state. Please be aware that the dentists of this state support the capital budget proposal for the state's assistance in building a new dental school at Marquette University. I received my dental training like the majority of dentists in Wisconsin; at Marquette School of Dentistry. If this were to change our state will suffer. We need this new educational and clinical facility to ensure that Wisconsin will remain a leader in dental education and maintain an adequate supply of dental care providers; dentists and dental hygienists. Please join with us in achieving this vital goal.

Thank you for your attention and the opportunity to address you today regarding the Governor's budget proposal for the upcoming state budget cycle.

P.S. Please see attached informational sheets.

SPECIFIC CONCERNS

The needy people of Wisconsin, especially the children and elderly, are increasingly experiencing pain and suffering. We must do something while there is yet time and the will to do it. Please help us to achieve this worthy goal.

1. **FILED FEES need to be kept current** and not lagging years behind the actual cost of care delivery. Reimbursement "filed fee" levels are currently based on the "filed fees" of 1991 (for adults) and for the "filed fees" of 1995 (for children). We can do this!
2. **INCREASES IN THE REIMBURSEMENT RATE should not be delayed** several months into the budget cycle due to delays in implementation by the DHFS. We can do this!
3. **REIMBURSEMENT LEVELS MUST INCREASE to the 85% level of "current" filed fees** in order to encourage enough dentists to join the program and ensure adequate delivery of care. We can do this!
4. **MORE THAN A 10% INCREASE in the dental MEDICAID funding is absolutely required** to ensure long term program stability. You simply can not serve more people with fewer dollars each year and still expect the need to be met. We can do this!
5. **DELIVERY OF DENTISTRY IS INHERENTLY DIFFERENT FROM THE DELIVERY OF MEDICAL CARE.** This difference translates into large differences in the cost of delivery. Approximately 70-80% of dentists in Wisconsin deliver care as general practitioners; the inverse of medical care delivery which is high on the specialty end. These practitioners are, for the most part, solo operations or small partnerships. Their practices run like miniature hospitals as far as intensity of labor and scope of procedures. But, they are not hospital based or clinic based. Hence, the only operational funding for their practices comes from fees for service—this is what directly pays the overhead. No government grants or other moneys are available to assist them in offsetting the current "operational expense gap" (the difference between Medicaid fee reimbursement and their hard costs of care delivery). Every dollar lost has a direct impact on practice viability i.e. the business of dentistry. We can do this!
6. According to information the dental profession has obtained from the LFB, **THE LANGUAGE OF THE CURRENT PROPOSAL MUST BE CHANGED TO REFLECT THE MONIES THE GOVERNOR'S BUDGET PROPOSAL HAS ALREADY ADVANCED** for the dental Medicaid program. This will allow for \$2,973,900 to be added to the dental Medicaid funding for the first year of the biennium budget and hopefully about that same amount, or greater, for the second year. We can do this!

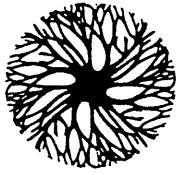
7. **THE SECOND YEAR "TIE-IN" OF "REIMBURSEMENT RATE INCREASE" TO THE FIRST YEAR'S INCREASE IN NUMBER OF RECIPIENTS TREATED** is not going to work. We need more time to convince dentists that the program has improved, get them certified, and train them in the paperwork before we will see any real increase in the number of dentists available to treat more people. It will take a little time, and real change, to convince them that we have changed our level of commitment and truly altered our course in a positive direction. We can do this!

8. **THE PAPERWORK LOAD SHOULD BE "USER FRIENDLY" AND NO MORE COSTLY OR CUMBERSOME THAN ANY OTHER DENTAL INSURANCE COMPANY NOW DOING BUSINESS IN WISCONSIN.** The huge paperwork burden has generated additional significant costs for providers, frustrating them to the point of leaving the program and deterring others from joining. The dental providers and their staff members have struggled beyond the limits of what is considered, to use a common insurance term, "usual and customary" in the business world. Nevertheless, they are a good group and will "try again" if a concerted, earnest effort is made to "fix it". We can do this!

9. **WISCONSIN CAN NOT AFFORD TO ALLOW ITS ONLY DENTAL SCHOOL TO FADE INTO OBLIVION.** We need to have a healthy School of Dentistry in Wisconsin. Marquette University is the logical partner in this venture; building a new dental educational and clinical facility. Every dollar the state spends will return multiplied to the people of Wisconsin. The state should support this effort to the fullest measure possible. The only caveat we might suggest is to locate the new facility out at the Medical College hospital / clinic complex. This would infinitely improve the dental school educational experience as it relates to facial and oral pain management, geriatric dentistry, pediatric dentistry, and hospital dentistry----areas of anticipated growth and need in the next century. Finally, there are possibilities for **coupling state funding support and/or tuition forgiveness with mandatory participation in the dental Medicaid program and/or practice location requirements in areas of demonstrated need.** This could help us solve the manpower distribution problem and simultaneously bring Medicaid dental services to the people who most need them in the poorer areas of the state. This is a WIN—WIN plan. And, we can do this!

4/12/99

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Wisconsin Primary Health Care Association

Testimony of Greg Nycz

Director of Family Health Center of Marshfield, Inc.

On behalf of Wisconsin Primary Health Care Association

Joint Committee on Finance Public Hearing

University of Wisconsin – Stevens Point

April 13, 1999

My name is Greg Nycz. I am the Director of Family Health Center of Marshfield, Inc. I am here today representing the members of the Wisconsin Primary Health Care Association. Our mission is to promote access to comprehensive community-oriented primary health care services for medically underserved communities in the state. Our members include health care providers from rural and urban Wisconsin who provide care to individuals who are financially, geographically, and/or culturally isolated from traditional health care services.

I want to call your attention to three issues of concern in the budget - dental access, the DHFS Well-Woman Health Screening program, and supplemental payments to health care providers who can prove an increase in the level of uncompensated care they've provided over the past year. For your information, I've submitted this testimony in writing to the page staff.

The lack of access to dental services for Wisconsin residents is reaching a crisis level. We support a multi-faceted approach to improving access to dental services for all the state's population. Modifying the Medicaid dental system (an issue I am convinced you have heard much about) is only one step to ensure that all Wisconsin residents have the ability to find dental providers who are willing and able to serve them. We are requesting \$500,000 in each year of the biennium to support creation and expansion of dental practices that serve all people regardless of insurance status or ability to pay. The state's federally qualified health centers, the model upon which to base this program, are already providing a significant amount of dental care to Medicaid and uninsured residents. In Medicaid for example, health center dentists constitute less than one-half of 1% of all dentists in the state but provide an estimated 7% of all Medicaid dental services statewide. We request state funds to expand health center dental services and encourage development of new practices in areas not currently served by health centers. These funds should be earmarked for any providers who are committed to caring for all individuals without regard to insurance or financial status.

Additionally, we recommend curriculum changes within Marquette University's School of Dentistry to focus on delivery of oral health services to all the state's populations - people who have both public and private insurance, those who don't have any insurance, and those who speak different languages. A public health focus for our state's only dental school is a critical piece of any educational system that desires to adequately train and prepare new providers for the challenges of caring for our states diverse population. We believe that with the state's increasing financial support of Marquette's Dental School, an expectation that graduating dentists accept Medicaid patients to assist the state in complying with the federal equal access

provisions of the Medicaid law is reasonable and makes for good public policy. After all, the state pays for Medicaid coverage and has a right to strongly encourage, wherever and however possible, dental providers to see those patients.

Our second issue of concern is the Department of Health and Family Service's Well Woman Health Screening Program. In the last budget, the Legislature approved a well-women health screening grant program. Funds were intended to be used to provide health screening, diagnosis, assessment and health education for women's health risks and would have been targeted to low-income, underinsured, and uninsured women. Applicants for these funds would have been required to have experience in the development and provision of health screening services to underserved populations. The Department, however, chose not to implement the program the Legislature passed, but instead intended to use the funds to reimburse health care providers, certified under an expanded Wisconsin Women's Cancer Control program. Unfortunately, DHFS did not spend any of the \$600,000 appropriated in 1997-98 for this program. It is our understanding that providers were not even certified until February of this year. We request that the Committee either direct the Department to comply with the last budget's plan or at a minimum, direct the Department to add \$600,000 to its current year appropriation for provider reimbursements for this year to ensure that women who need these services can get them.

And finally, the budget contains funds for outpatient services provided by hospitals who are experiencing increasing financial burdens related to providing more services to Medicaid recipients and other low-income individuals with little or no insurance. The Governor's budget acknowledges this problem by providing a supplemental outpatient payment to acute care hospitals. We're here to tell you that all outpatient clinics are experiencing increasing numbers of uninsured and we request the Committee's help to expand this budget language and appropriation to allow all outpatient providers who can prove an increase in uncompensated care to take advantage of this funding.

Thank you for your time. I would be happy to take any questions.

-Host Drug Master File

Cut Ext.:

Code: PROZ10 Brand: PROZAC 10MG CAP DIST

Sub: Generic: FLUOXETINE HYDROCHLORIDE

NDC: 00777-3104-02	Pack: 100				
STD: - -	Pack:	New Store: Y	Verb: TAKE		
GPI: 58160040000110	Dec:	Status:	Unit: CAPSULE		
UPC#:	Unit: CAP	Store Gen:	Units:		
Strn: 10MG	UPC:	SUBS Srch:	Route: BY MOUTH		
MFG: DISTA	DESI: 2	SamePack:	Conv:		
Lot#:	Equiv:	Brand Pct:			
ExpDays:	Sched: 6	MAC:	/ /		Y
Expires: / /	Reorder:	AWP: 252.41	01/14/1999		
DC Date: / /	Price: J	Region: 1	Cost: 213.49	84.58 %	M
CostUpd: 04/12/1999	Comp: Y		Std: 252.41	100.00 %	Y
HostUpd: 03/29/1999	Multi: N		Reg: 252.41	100.00 %	N
LastUpd: 04/12/1999	Warehs:	Group:	Wel: 252.41	100.00 %	Y

FIND UPDATE ADD SEARCH PAGE 2 OPTIONS CUT CLEAR
rug Record Updated

Shown above is a print screen of the entry for Prozac 10mg in the drug file. You will notice the AWP (Average Wholesale Price) of \$252.41 and the Cost (Acquisition) of \$213.49. Notice next to the Cost of \$213.49 field the 84.58 % which represents the cost as a percentage of AWP. If we were purchasing at AWP-18%, the figure would be 82%.

If we dispense 30 capsules, the cost ($\$213.49 \times .3$) is \$64.05, while AWP-18% is \$62.09. If we add the dispensing fee of \$4.38 to the \$1.96 we lost on the cost of the drug we find we made \$2.42 with a gross profit margin of 3.78%.

If we dispense 60 capsules, we lose \$3.92 to cost, add a fee of \$4.38 and produce a profit of 46 cents with a gross profit margin of 0.36%.

With an average cost of filling a prescription in the \$4.50-\$5.00 range, Copps would lose \$4 every time we filled 60 Prozac 10mg for a Medical Assistance patient.

THE COPPS CORPORATION

**2828 Wayne Street
Stevens Point, WI 54481**

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715-344-7378 Fax

**Jay V. Wolfe, RPh
Pharmacy Director**

Senator Kevin Shibilski
Representative Julie Lassa

The Copps Corporation requests your assistance in eliminating a Medicaid budget proposal which attempts to balance the Medicaid budget on the backs of Wisconsin pharmacists.

We have recently learned the Wisconsin Medicaid officials have proposed to slash pharmacy provider reimbursement drastically in the next state budget. The current reimbursement rate is AWP-10% plus a dispensing fee. AWP is the average wholesale cost which is determined nationally by averaging the listed wholesale price from major drug wholesalers. A discount off of AWP reflects the marketplace in that few, if any, pharmacies buy at wholesale. To survive, pharmacies must be big enough to negotiate a discount off of wholesale. The current AWP-10% is an attempt to determine a more accurate acquisition cost. Generic, multi-source drugs are not reimbursed at an AWP-10% rate, but rather a Maximum Allowable Cost (MAC) which is typically determined by HCFA.

The proposed rate is AWP-18% plus a dispensing fee. I can tell you that The Copps Corporation will fill a half million prescriptions in Wisconsin this year, and we will not have an acquisition cost of AWP-18%. A reduction in the discount from 10% to 18% is not only drastic, but fails to address the marketplace reality.

One can only assume that a reduction in the dispensing fee means Medicaid believes pharmacists in Wisconsin are providing too much service to Medicaid patients. In an era where health care officials proclaims the many benefits of pharmaceutical care in reducing the total cost of care, it is unique that Wisconsin wishes to diminish that care.

Pharmacy in Wisconsin already struggles with a hopelessly inadequate and outdated Medicaid claims processing procedure. Pharmacists submit paper or tape claims to EDS which processes the claims and returns remittance advices with rejection notices some weeks later. Long after the customer is gone, pharmacists know that they have a problem. Medicaid in other states have been providing point of sale adjudication for years, giving the pharmacist the results while the patient is still in the pharmacy. Yes, Wisconsin Medicaid will begin testing this soon in a few counties. Meanwhile, pharmacists daily deal with write-offs for claim problems they will never be able to collect on.

As taxpayers, we all would like to see the Medicaid budget reduced. Reducing the budget by paying pharmacists less than cost or less than reasonable is likely to reduce the amount of pharmaceutical care available. Many providers who cater primarily to a Medicaid population will be forced out of business. Many providers will discontinue providing services to Medicaid patients. Others will reduce the quality and quantity of service and care. Long term, the results will be the same as with the oil filter commercial: "You can pay me now, or you can pay me later." Instead of paying for the \$5.99 oil filter, you can pay for a new engine. Instead of paying a reasonable fee for prescription service, you can always pay for the emergency room.

As taxpayers, we are impressed with the Wisconsin Works program which reduces the Medicaid budget by putting people to work. This is +the right direction to go.

I hope that you will support a realistic reimbursement rate for Medicaid providers, a rate which will allow continued access for Medicaid recipients to the most cost effective sector of health care.

Sincerely,

Jay V. Wolfe, RPh
Pharmacy Director

cc: Governor Thompson



Saint Joseph's Hospital
MINISTRY HEALTH CARE

Sponsored by Sisters of the Sorrowful Mother

Senator Kevin Shibilski:

Tuesday, April 13, 1999

Good morning. My name is John Skaden and I'm the chief financial officer of Saint Joseph's Hospital of Marshfield. I'd like to first thank Senator Shibilski for offering us this opportunity to discuss our financial concerns as they relate to the up-coming State budget and Medicaid.

Each year, Saint Joseph's Hospital provides approximately \$12.5 million dollars of healthcare services to about 1,400 Medicaid patients who reside in Central and Northern Wisconsin. Over 70% of the healthcare we provide to these Medicaid patients is derived from six services: neo-natology (\$2.7 million), pediatrics (\$2.1 million), orthopedics (\$912,000), neuro-surgery (\$835,000), general surgery (\$810,000), and obstetrics (\$745,000). Our average payment for treating inpatients enrolled in the Medicaid program is about \$4,500 while our average cost to provide these services is about \$5,800 per patient. We have lost between \$2.1 - \$2.6 million dollars per year providing healthcare services to Medicaid patients over the last three years. These losses result in about \$5 million dollars of cost-shifting to non-government payers each year.

Given the preceding facts, we have several concerns we would like to express this morning relative to the proposed Medicaid healthcare bi-annual budget for years 2000 - 2001. First, most hospitals will incur an average of about 2.5% cost increase from their vendors. Governor Thompson is proposing a 0% increase in the inpatient base payment rate to hospitals in both years of the budget and a 0% increase in payment for outpatient services in FY 2000 and a 1% increase in FY 2001. This disparity between cost increases and payments from Medicaid will potentially result in an additional \$470,000 cost-shift to the non-government payers. We would recommend an increase in the base payment rate equal to the Healthcare Consumer Price Index. This is only consistent with the uncontrollable cost increase we will incur as providers of health services.

Second, we are concerned about the Governor's proposal to reduce funding for graduate medical education. Although the real cost of indirect medical education is extremely difficult to quantify, a 25% reduction will certainly only result in further cost-shifting to other members of society. It is our belief that both the private and public sector should equally share in this cost.

April 13, 1999

Joint Finance Committee
Public Hearing -U.W. Stevens Point

RE: Governor's Budget

Dear Committee Members:

I am writing you because I was not able to speak before you due to my responsibilities at work. I am representing a number of people who are dealing with Alzheimer's Disease. I have been the facilitator for the Portage County Alzheimer's Caregiver Support group since 1990. I have been on the board for the Alzheimer's Association, Midstate Chapter since 1992. We would like to ask you, when you go over the Governors budget, to look at the facts:

*"80% of Medicaid long term care is going to pay for institutional care" (All quoted remarks will be a national statistic from the Alzheimer's Association). We all believe that Wisconsin Long Term (LTC) system needs some improvement. However, it is kind of strange when the federal government is basing their Long Term Care programs on the Wisconsin COP program. Isn't that saying something to us! We are requesting you to make sure that the budget states LTC redesign as pilot only and not a statewide implementation. If we are going to change this great program lets do it right Vs creating a monster no one wants to be associated with it.
FUND AS WORKING PILOTS NOT A STATEWIDE IMPLEMENTATION

*The major concern we all have is where is the money coming from to fund the LTC program? Will there be enough money for services for all the individuals who will need it? I am aware there will be categories of eligibility. But, is this program ready to deal with the cancer patient who only six months ago was diagnosed with the disease. And, today, they need hospice and 24 hour supervision because of cognitive impairments. Will there be enough money to deal with the individual who has Alzheimer's who need 24 hour supervision and who refuses to leave her/his own home. Please keep in mind there are about 100,000 individuals in Wisconsin who have Alzheimer's. **BEFORE LTC REDESIGN IS UP AND RUNNING, PLEASE MAKE SURE THERE WILL BE MONEY AVAILABLE TO HELP THE PEOPLE IT IS DESIGN TO SERVICE.**

*The Governor feels the State will be saving a lot of money by having people move from nursing home back to community based care. Does the Governor understand the people residing in nursing homes who do not need the skill nursing services are people who need custodial care due to a cognitive impairment? This means the individuals would still require 24 hour supervision if taken out of nursing home care. The cost for that service is still on the high end but might be cheaper than nursing homes. "Substituting assisted living for nursing home care **COULD** save from \$3.5 billion to \$5 billion yearly." "States that have made a concerted commitment to home and community based care (WI, OR, CO) have reduced projected nursing home use between 18% and 39% and have saved 9% to 23% in projected long term care costs." **IN MY OPINION, THE GOVERNOR IS GAMBLING WITH PEOPLE AND THEIR HOPES IF HE FEELS THAT THE SAVING (TAKING PEOPLE OUT OF NURSING HOMES) WILL BE ENOUGH TO CREATE THE FUNDING POOL FOR THE LTC REDESIGN.** Please keep in mind, the rural areas might only have nursing home care.

*"The average lifetime cost for a person with Alzheimer's disease is \$174,000. The average annual cost of nursing home care for a person with Alzheimer's is \$42,000." Alzheimer's families have always had the desire to have an equal balance with community based service and nursing home services. On the other hand, what happens with this disease is families are torn apart. (Emotionally draining, afraid 'Am I going to get the disease, to simply can not deal with the disease.) Usually, there is one person who is able to deal with the disease. This creates a high rate of caregiver burn out. To decrease early admission to nursing homes we need to provide caregivers the opportunity for respite. **WE NEED TO HAVE AN INCREASE IN THE A COP AND ALZHEIMER'S FAMILY AND CAREGIVER SUPPORT PROGRAMS (AFCSP) TO DECREASE THE COST OF SERVICE NOW.**

Joint Finance Committee Members, thank you for taking the time to travel around the State to listen to people discussing the Governor's budget. Please take into consideration what everyone has said to you. I am sorry I was not able to stay the whole day at the hearing. Please contact me if you have any questions.

Sincerely



Linda Hoppenrath, 2907 Cherry St. Stevens Point WI 54481
(715) 345-5825 W (715) 344-1162 H

A Daughter's Odyssey, a Home for Dad

By ELLEN GRAHAM
Staff Reporter of THE WALL STREET JOURNAL

STAMFORD, Conn.—Seldon "Scotty" Faulkner was stripped to his undershorts, soiled with his own excrement and crying. The 69-year-old retired college professor, who suffers from Alzheimer's-type dementia, had forgotten how to get into his pajamas. And just then, no aides were available to help him at the \$6,800-a-month nursing home where he had been living for about a week.

The 85-bed nursing home here was just one stop on a sometimes-surreal trip

FAMILIES

through the long-term-care system for Mr. Faulkner, his 40-year-old daughter Julia, her husband and her brother. The family's effort to find him a permanent home would run the gamut of available dementia care, turning Mr. Faulkner into a vagabond shuttling from facility to facility. And it was greatly complicated by his combative symptoms, a common stage of his incurable, fatal disease.

His odyssey has been harrowing but, in the end, also astonishing and heartening. Quite by chance, the family finally stumbled into a rare pocket of progress—a new approach to managing elderly people with memory disorders that, in Scotty Faulkner's case, brought him back from the abyss.

The story of his plight has huge implications for a retrenching long-term-care system, now on a collision course with what one geriatrician calls a "demographic bulldozer." Alzheimer's and other types of dementia are set to explode in the nation's aging population. Some 4 million Americans are now afflicted, and 14 million cases are expected by the middle of the next century.

When families can no longer manage demented loved ones at home, they typically wind up in institutions that were never meant to take on their care. Geriatric psychiatrists Joel E. Streim and Ira R. Katz of the University of Pennsylvania point out that nursing homes were originally designed for people who were sound of mind but suffering from chronic medical illnesses. Yet today, one-half to three-quarters of the nursing-home population has dementia, 25% to 50% of them with psychotic symptoms that can challenge the very best institutions and overwhelm the mediocre.

In an era of stringent cost-containment, financing such care already is growing problematic. Medicare, the government health insurance for the elderly, doesn't cover the kind of long-term "custodial" care that most dementia patients require—supervision and help with tasks of daily living. Instead, patients usually exhaust their own savings and wind up on Medicaid, the government program for the poor that picks up the tab for about two-thirds of all U.S. nursing-home residents. To control ballooning Medicaid budgets, many states have simply halted construction of new nursing-home beds.

Meanwhile, a flurry of mergers and acquisitions in the past few years has left 10 publicly traded companies in control of around 20% of the nation's 1.8 million nursing-home beds. Eager to show stockholders robust returns, these companies are seeking to fill beds with more private-pay and Medicare patients needing short-term medical treatment, rather than Medicaid-dependent residents requiring years of labor-intensive custodial care.

For patients and their families, one of the cruelest ironies of dementing illness is that its symptoms can themselves disqualify patients from obtaining dignified care. Mr. Faulkner, for example, has a type of dementia that struck relatively early in life and progressed rapidly, leaving him confused but ambulatory and more robust than someone wheelchair-bound or bedridden. Agitated and restless, he walks until he drops from fatigue. Sudden noises or movements—even a stray book on his night stand—can trigger anxiety. He can be talkative and friendly, but the words rarely make sense. In short, he is not the sort of patient that most institutions eagerly embrace.

After one nursing home rejected his application because he didn't fit its criteria, his daughter said of the arduous admissions process: "It's beginning to seem like a beauty pageant."

Before he retired four years ago, Scotty Faulkner was chairman of the theater department at the University of Arkansas in Little Rock, a career that could not have been foretold by his upbringing. Born in 1929 in St. Louis, he was 12 when his father, a prison guard, committed suicide. His mother died a year later, and he was raised in poverty by an older brother. At 16 he left school to enlist in the Army. Stationed in Salzburg, Austria, during the Allied Occupation, he got his first taste of symphonic music, opera and theater, and it would change his life.

Back home, he attended college on the G.I. Bill, eventually earning a Ph.D. He founded the theater arts department at the University of Wisconsin branch in Stevens Point, where he booked world-class artists such as conductor Eugene Ormandy to perform on campus. His wife, Julia's mother, Dona, died of cancer 10 years ago. She was the extrovert of the pair, and her death left Mr. Faulkner isolated and depressed—factors that his daughter now believes may have hastened his descent into dementia.

That descent began shortly after his retirement, when Julia and her husband, Andy Bouvet, were living in Europe. Julia, who now is a soprano on the roster of the Met-



Seldon 'Scotty' Faulkner



Julia Faulkner

At one facility, Mr. Faulkner climbed a wall and fell, cracking three ribs. His unit was for mild to moderate memory disorders. 'This was beyond moderate,' said the general manager.

ropolitan Opera in New York, was then singing with the Vienna State Opera, while Andy did graduate work in European history. Word of her father's decline came from relatives in Mount Horeb, Wis., where Mr. Faulkner was living with his mother-in-law, Julia's grandmother, now 96. He would incessantly repeat questions, was driving erratically and locking himself in his car or garage, dialing 911 whenever he'd get in a jam. The police and other townsfolk looked after him, guiding him home if he got lost on a walk.

JULIA, ANDY AND their infant son, Danny, moved back to the U.S. in the summer of 1997. Last fall, during a visit to Wisconsin, she pressed Mr. Faulkner's doctor. "Are we talking about the A word?" He said he thought they were. She insisted that her father give up driving, hired a housekeeper for him and her grandmother and returned home to Connecticut with foreboding.

The current crisis began in early June, when Mr. Faulkner wandered into the middle of a boisterous schoolyard soccer game. "In his distorted perception, it turned into something like a war, where people were being killed and hurt," his daughter recalled. He became highly agitated and was given a heavy dose of Ativan, a tranquilizer that Julia later learned can exacerbate psychotic symptoms in geriatric dementia patients. She flew out with 16-month-old Danny, determined to take her father

to Connecticut to live with them.

She quickly abandoned that notion. He didn't recognize her the first day. In the middle of the night, he climbed onto the edge of the bathtub, knocked down the shower rod and fell, screaming, into the tub. Keeping him out of harm's way at home, she realized, would entail following him around with her hand on his shoulder 24 hours a day. She feared for his safety in their two-story townhouse in Stamford. "I knew it would destroy my family," she says.

The next 10 days were a whirlwind: packing Mr. Faulkner's belongings, readying his house for sale, arranging for her grandmother to move in with an uncle in Virginia. She and her brother John, who lives in Atlanta, found Mr. Faulkner an "assisted living" facility in Stamford called Brighton Gardens, one of 107 senior residences operated by a division of Marriott International Inc. A brand-new, luxurious facility, it had vacancies in its special unit for memory disorders, where his single room and bath cost \$4,470 a month. Julia told her father she was taking him to a place near her home that was as nice as a hotel. He seemed genuinely relieved.

If the long-term-care industry has a growth niche, this is it. Many providers, in both the public and private sector, are moving swiftly into assisted living. By some estimates, more than 30,000 residences have sprung up around the nation, with most growth in the past five years. Offering private rooms, meals and help with tasks of daily living to people who generally pay their own way, such facilities charge less than nursing homes but have lower overhead, less regulation and a much more enticing image. A number of states have begun to allow Medicaid funds to be used to finance such care.

The industry also has begun to target the surging Alzheimer's market with stand-alone facilities or "special care" units costing up to

50% more per month than ordinary assisted living. Some offer small-scale, homelike environments with a staff trained to handle difficult behaviors like agitation and aggression. Some can't—or won't—take the hard cases. Others deliver nothing special at all, beyond a locked hall that segregates unruly residents from the others.

Financially, at least, Mr. Faulkner was well-qualified for assisted living. He has a retirement annuity that, combined with Social Security and interest on other assets, yields \$6,200 a month for life. That means he can pay for long-term care out of pocket, affording him a modicum of clout in a system whose customers usually depend on Medicaid.

BEFORE HER FATHER moved into Brighton Gardens, Ms. Faulkner filled out a checklist about his habits, likes and dislikes. Beyond reviewing his medical records, at no time did the admissions staff assess her father in depth, she says. On the day he was admitted, Mr. Faulkner's family stayed with him through dinner. An aide told them to slip away when he wasn't looking.

The next day, he tried to escape. He attempted to climb onto a knee-high stone ledge near a 7-foot fence enclosing the facility's outdoor "wander garden" and fell, fracturing three ribs. The only witness was another resident who alerted the staff, reporting: "He was trying to get out."

An aide took him to a nearby hospital emergency room, and left him there. By the time Ms. Faulkner and her brother arrived, he was on a stretcher with restraints around his chest, bellowing in pain.

After scuffling with a hospital orderly, he was heavily sedated with the antipsychotic Haldol and returned to Brighton Gardens. The next morning, he became threatening and agitated, appearing to see things that weren't there and throwing cups and saucers, according to Marjorie Simpson, general manager. "Our special-care unit is meant for mild to moderate memory disorders," she says. "This was beyond moderate."

Surrounded by resort-like amenities, she adds, some mildly demented assisted-living residents "think they are on a cruise." As for Mr. Faulkner, "we were not designed to take care of what he presented us with."

Ms. Simpson says that it was only after the fall that Brighton Gardens' staff learned from his family that Mr. Faulkner had been abruptly taken off the antidepressant Zoloft shortly before he left Wisconsin. This and the move, she suggests, could have triggered his unusual behavior. Ms. Faulkner says his medications were noted on his charts that were forwarded to Brighton Gardens.

She was upset when a Brighton Gardens official suggested on the day of the fall that his symptoms looked more like psychosis than Alzheimer's. He was scheduled for an evaluation by a psychiatrist.

"Oh my God," Ms. Faulkner thought, devastated. "Has he been schizophrenic all this time?" Later, a geriatric social worker explained to her how Alzheimer's often manifests itself with psychotic symptoms.

The consulting psychiatrist found Mr. Faulkner too disoriented to assess. The state requires assisted-living residents to be certified by a physician as stable and chronic—that is, not in need of acute care, Ms. Simpson says. Because Mr. Faulkner didn't meet those criteria, she adds, "he couldn't return to the community." The psychiatrist arranged to have him transferred by ambulance to a psychiatric hospital in the private, not-for-profit Masonic Geriatric Healthcare Center in Wallingford, Conn.

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Scotty Faulkner's Long Odyssey Home

Continued From Page B1

about an hour from Stamford.

At Masonic, with its abundance of therapists, richly carpeted corridors and private rooms, his progress was remarkable. On one visit, Ms. Faulkner found him chatting amiably at the nurse's station, where they had been playing tic-tac-toe. He beamed at the sight of Julia and gave her a big hug. He kept saying, "The kids just did wonderfully, and I didn't have to do much of anything," as though recalling a long-ago student production. His biggest problem: "I can't get the bathroom in the right place." When words would fail him, he'd draw on an actor's repertoire of pantomime and body English.

Ms. Faulkner was struck by his apparent acceptance of his surroundings. His medication had been fine-tuned, and he wasn't clawing at the doors to get out. The hospital is an acute-care medical facility where the \$700-to-\$800-a-day fees are covered by Medicare. But it doesn't provide custodial care, and after a month it was ready to discharge him as soon as a nursing home could be found. The hospital's affiliated long-term care residences—500 beds ranging from apartments to skilled nursing—have a combined waiting list of about 1,000 names.

"If he could stay here the rest of his life, what joy," Ms. Faulkner said that day at Masonic. "In no way do I expect him to get any better than today." She feared that without daily therapy, he'd relapse, and was pained by the Catch-22 that as soon as he improved he must move on.

As she prepared to leave that day, Mr. Faulkner became tearful, saying, "I wish I had more going for me." Ms. Faulkner nodded sadly. "Take what you can get, Dad," she said, touching his hand.

With the clock ticking, she redoubled her efforts to locate a nursing home. She had applied to several in the Stamford area with special Alzheimer's units, but was learning that such a search is best done long before a crisis occurs. For several years, Connecticut has had a moratorium on new nursing-home construction, while directing more Medicaid dollars into less-expensive home care and day programs. But people like Scotty Faulkner are too sick for these alternatives.

Most Stamford nursing homes were full, with waiting lists as long as a year and a half. One facility that costs over \$8,000 a month she ruled out as unaffordable. She had her heart set on the nonprofit St. Camillus Health Center, operated by the Diocese of Bridgeport and five

Mr. Faulkner struck a nurse who intervened in his ruckus with his roommate. Later, his account of the incident was confused. 'She threw the first punch!' he said.

minutes from her home. But after reviewing Mr. Faulkner's file documenting his recent hospitalization, St. Camillus rejected his application.

In a letter, St. Camillus said it was trying to become restraint-free, didn't have a psychiatric nurse on staff and wasn't equipped to meet his needs. Federal reforms enacted in 1987 discourage use of physical or pharmacological restraints. While more humane, the regulations have made management of difficult behaviors all the more taxing without an abundance of specially trained staff.

Carol Scott, who was then the admissions coordinator at St. Camillus but has since left the facility, says she had agreed to reconsider Mr. Faulkner's application at his daughter's request. But additional information that St. Camillus needed was not forwarded by the family, she says.

That's because by then, Ms. Faulkner had learned of an available bed at another Stamford facility. On a steamy day in July, she set out to investigate what seemed to be her father's sole option: Homestead Health Center, operated by Vencor Inc., based in Louisville, Ky.

While it doesn't have a special Alzheimer's unit, Homestead has a nurse on duty 24 hours a day in each unit, plus one aide for every eight residents. Ms. Faulkner's tour guide acknowledged the cramped hallways and nondescript decor. "We don't have chandeliers," she said, stressing instead the quality of the staff, some of whom had been there for 20 years.

Ms. Faulkner was shown the semi-private room her father would occupy. His roommate-to-be, she was assured, has "a great sense of humor." As soon as Mr. Faulkner's financial records could be faxed from the hospital, he would be cleared for immediate transfer.

LATER, in the Homestead parking lot, Ms. Faulkner confirmed her reservations. The place seemed crowded, and at \$229 a day for a semi-private room, she said, "I'm frankly disgusted by the costs here in Connecticut."

Because he was being discharged from a hospital, her father qualified for a maximum of 100 days of Medicare reimbursement, so long as he required medically necessary skilled nursing care. It would pay the full cost of his first 20 days at Homestead, after which his co-payment would become \$95.50 a day. When his care reverted to "custodial," or after 100 days, he would have to pay the full rate.

Ms. Faulkner and her brother had talked about transferring their father to a state where rates are lower, once he declined to a point where he wasn't aware of his surroundings. Sounding emotionally drained, she said ruefully, "It must sound like we think of Dad as a piece of luggage."

A few days later, Mr. Faulkner was settling in—happily—at Homestead. Julia, Andy and Danny appeared for a visit, only to learn that there already had been trouble. Mr. Faulkner had arisen in the middle of the previous night and tried to rearrange his sleeping roommate's covers, pulling them over his head. A tussle ensued, and when a nurse tried to intervene, Mr. Faulkner hit her.

The Alzheimer's Explosion

Americans with Alzheimer's	4 million
Cases projected by 2050	14 million
Percentage of people over 65 with Alzheimer's	10%
Percentage of people over 85 with Alzheimer's	50%
Number of new 85-year-olds each year	100,000 to 120,000
Average life span after onset of dementia	8 years
Nursing-home residents with Alzheimer's or other cognitive disorders	50%
Average annual cost of nursing-home care, per capita	\$41,000
Total nursing home beds, 1996	1.8 million
Total nursing home beds, 1986	1.7 million
Projected growth of nursing-home care expenditures, 1998-2007	70%*

*\$87 billion to \$148 billion

Sources: Alzheimer's Association; John Ransom, Raymond James & Associates; Health Care Financing Administration; American Health Care Association

who was merely confused and depressed. Complaints, she figured, wouldn't change fundamentals like the building's design or staffing levels.

She visited him twice daily, sometimes scrubbing out his bathroom herself. When an aide was trying to spoon-feed several residents at once, Ms. Faulkner pitched in. One day her father's glasses were broken and nobody seemed to know how it had happened. Another day she found him wearing his roommate's shoes. (But both shoes were for the right foot; his roommate was an amputee.)

"His ability to love comes in very small packages these days," Ms. Faulkner said. Her father had told her that day that no one had ever been as kind to him as she had. "That's probably true in terms of what's needed," she said, "but my mother would have done much more. I'm constantly judging myself against her, and every day I fail in some way."

IN AUGUST, Ms. Faulkner had a singing engagement at a music festival near Seattle. Andy, who works for a consulting firm in Stamford, visited her father most evenings. While she was away, a Homestead social worker called her in Seattle to suggest that she hire a companion to work with her father a few hours a day to give him more one-to-one stimulation. A private-duty visiting nurse, Ms. Faulkner figured, would run at least \$500 a month more.

Bringing him to Connecticut had been a dreadful mistake, she decided. She had thought his quality of life would be better with her nearby. "I see now it was more for me than him," she said.

Meanwhile, a cousin in Wisconsin had suggested what sounded like a promising alternative: A new nonprofit dementia facility in Madison, designed as a cluster of homes, each one accommodating only eight residents and two to three staff members. The cost: \$3,025 a month—less than half the fee at Homestead.

Her resolve to move him was sealed upon her return from Seattle. While he had stabilized somewhat after the first few weeks at Homestead, she was now appalled by his decline. His medication had been changed again, from oral Haldol to Ativan and BuSpan, anti-anxiety drugs. He had lost weight, and it was hard to sort out the effect of drugs and environment from the progression of the disease. She found him incontinent, unable to speak or feed himself, tethered with canvas restraints in a wheelchair, head down.

One afternoon, Mr. Faulkner sat with a frozen face, unresponsive to his daughter's efforts to draw him into conversation. Finally, she said gently, "Dad, how would you like to go home to Wisconsin?" He was silent for a long time and then whispered, "I wouldn't mind."

Still, there were no promises. Appletree Villas, the Madison home, gave him only a tentative yes. By state law, restraints are prohibited there, and the place is intended to serve patients who need no more than three hours of skilled nursing a week. They would have to assess him in person.

It was a gamble that Ms. Faulkner accepted. Homestead officials declined to comment on Mr. Faulkner's care. Susan Moss, vice president for corporate communications at Vencor, which acquired Homestead in 1995, says: "As a matter of policy, we don't comment on patient records or files, due to issues of patient confidentiality." A new administrator started at Homestead on July 1, she adds, and while "getting to know the residents and their needs, is trying to evaluate what changes might be necessary."

The Homestead staff was unaware of Ms. Faulkner's dissatisfaction, Ms. Moss says. She never made a formal complaint—either to Homestead's administrator or on the 24-hour hotline that Vencor maintains for that purpose, Ms. Moss says. She and a Vencor clinical consultant, Clare Hendrick, stress that frequent transfers can be especially traumatic and destabilizing for dementia patients. Further, they point out that providing effective care requires time to become familiar with an individual resident's needs. "It's hard to measure success when someone is there for only about a month,"

where the villa's seven other residents eat family-style. But from the beginning, she says, "we've seen absolutely no aggression."

That could be because the house is very much a home. Each resident has a sunny private bedroom that leads into a large communal living room and open kitchen, from which the aroma of popcorn or homemade cookies often wafts. There are lots of overstuffed chairs, plus a small patio with a picnic table, a garden and a glider swing. Besides Ms. Jacobs, two house assistants are on duty each shift. Their orders seem to be to cater to and cuddle their frail charges, while encouraging them to do as much as possible for themselves. (With regular reminders, for example, Mr. Faulkner's daytime incontinence has disappeared.)

On a recent morning, Mr. Faulkner—now 10 pounds heavier than when he arrived—does a bouncy little two-step to the beat of the swing music coming from the living-room stereo. He greets a visitor, Jean Clark, who lives nearby, and to her amazement, is able to tell the staff that she is his sister-in-law. Lunch is being fixed in the kitchen, and with a grin, Scotty says, "Let's do lunch." His chart had noted that he had to be fed soft or pureed foods at Homestead. Here, fork in hand, he sits at the table and polishes off breast of chicken and vegetables, feeding himself with just a few reminders from a staff member seated beside him. Earlier, he had helped to set the table and had done a little vacuuming.

Villa 200's beds are an apt metaphor for the common-sense philosophy here. Instead of costly hospital beds with side rails—used in many nursing homes although they pose a danger of strangulation to the elderly—Scotty and the others sleep on mattresses and box springs resting on the carpeted floor. A body pillow is arranged next to their beds while they sleep to cushion them, should they roll out.

Another difference from the usual institution: Care is tailored to each resident's needs at the moment, rather than expecting them to hew to rigid procedures designed mainly for staff convenience. One caregiver has found that Scotty settles down for sleep better if she sits beside him for awhile. They have discovered he enjoys being read to, and they've bought him fragrant body lotion because the sense of smell is one of the last to disappear as the disease progresses. Ms. Jacobs says they have

At Appletree Villas, Mr. Faulkner was dancing and once again able to feed himself. Greeting his sister-in-law, he grinned and said, 'Let's do lunch.'

learned not to approach him suddenly from behind, explaining, "Scotty scares easy."

For other residents—who are grouped according to the severity of their dementia—there are different discoveries, different strategies. When a few men showed interest in weed-pulling, a section of the grounds was allowed to become overgrown. The residents put in a full day yanking out the weeds. Even residents in the late stages of the disease can enjoy music, sitting in the sunshine, having their hands held.

For about a decade, the state of Wisconsin has permitted counties to use Medicaid funds to support people with dementia in small, community-based residential facilities like Appletree. Roughly 40 such residences solely for dementia are now scattered around the state. Close to half of Appletree's 56 residents get Medicaid assistance.

Roger Stephens, executive director of RFD, explains that until recently, Alzheimer's care tended to follow the nursing-home "medical" model, because "that's what got paid for." Now, with the growing realization that smaller, less restrictive settings produce better outcomes at lower cost, the dollars are being reallocated here and in some other states.

A Madison nursing home typically charges private-pay residents about \$4,000 a month; a for-profit assisted-living facility runs about \$3,500—still several hundred dollars a month more than Appletree. Though it has been open only since January, Appletree now has a waiting list.

One afternoon, his daughter said gently, 'Dad, how would you like to go home to Wisconsin?' He was silent for a long time and then whispered, 'I wouldn't mind.'

When Ms. Faulkner tried to talk to her father about the incident, his account was confused. He said of the nurse: "She threw the first punch!"

There was barely room for the family in Mr. Faulkner's quarters, a space perhaps 8 feet by 12 feet furnished with a bed, a night stand, a chair, a bureau and a desk. He was tense, flinching with each sudden noise, as aides and janitors kept up a steady din in the hall. "I want to get the hell out of here," he said.

All the seats in the common room on his unit were full. Mr. Faulkner shuffled into the adjoining wing, where a going-away party for one of the nurses was in progress. He took a seat, dozed briefly and then stood, cup in hand, though about to make a toast. He lost his way halfway through the speech. One resident kept telling him to sit down. Finally another woman at the table silenced her by asking: "Oh leave him alone. He's new, and he's here with his daughter." From the sidelines, Ms. Faulkner whispered, "He has a defender!"

As the party broke up, Mr. Faulkner grew expansive. He hugged a couple of nurses, and greeted a woman in a wheelchair, who smiled and said gaily, "He's always talking to me!" Back in his room, he muttered, "Well, things seemed to work out. We've had a good session."

For someone given to compulsive pacing like Mr. Faulkner, Homestead's layout was a straitjacket. There was scarcely room to move in the long corridor, where a large receptacle for soiled diapers was permanently stationed outside his door. Nor, his daughter lamented, did the residents seem to belong "with women who have shrunk into skeletons who lie in their beds and don't say a word." Though she described Homestead's nurses as "unfailingly kind," she said the needs of terminally ill residents inevitably took precedence over someone like her father.

Ms. Hendrick says.

On the last day of August, Ms. Faulkner and her father boarded a plane for Chicago. The trip was agonizing; he tried to unbuckle his seat belt and got up every 30 seconds or so. She had to lift him into a wheelchair at the airport herself before driving on to Madison.

He was unresponsive and unable to stand by the time they arrived at Appletree's Villa 200, one of eight brick-and-stucco houses in the complex operated by RFDI Inc., a nonprofit provider of services for the developmentally disabled and elderly in the area. Meeting him face to face that first afternoon, Judy Willborn, the program administrator for elderly services, recalls that "psychosis was never part of my thinking about Scotty." His records noted delusional symptoms and a "poor" prognosis for rehabilitation. But his behavior issues, she felt sure, were related to his medication and being moved so often that summer. Scotty was in.

Susan Jacobs, the house manager of Villa 200, says her first thought upon meeting him was, "Time for a drug holiday." Indeed, after an examination by a geriatric specialist at the University of Wisconsin, Mr. Faulkner was taken off all medications except vitamins. The idea was to assess him drug-free, and slowly reintroduce medications as needed.

He was a handful at first, Ms. Jacobs recalls. As the drugs wore off and he returned to his incessant pacing, she says, "you had to feed him on the go," following him around because he refused to sit at the dining table

THE MAIN OBSTACLE to reproducing such villages everywhere, Mr. Stephens says, is finding and keeping caring staff in a field where burnout is the norm and wages low. Turnover of 50% a year is typical; Appletree's goal is to cut that to 30%. The state requires that employees get 56 hours of training before they begin working with residents, so each hire is an expensive outlay within RFDI's \$2 million-plus annual budget for senior programs.

While the hope is that every resident can stay for the remainder of their days, Mr. Stephens adds: "We don't have magic—there are people we cannot manage." Should a resident develop a severe medical illness or dangerous behaviors, he or she might have to be referred to a nursing home or psychiatric hospital, he says.

Is Scotty Faulkner happy here? Probably as happy—if that's the word—as anyone with his disease can be. On her most recent visit, his daughter concluded that he has reached the painful point where he realizes that the last vestiges of his reasoning are slipping away. He kept after her, pestering her not to let him forget, to be sure to remind him—about something he couldn't articulate. Finally it came to him: "I love you," he said.

Now medicated with low doses of Mellaril, an old-line antipsychotic, and trazodone for anxiety, he has made striking gains in strength and independence. But he still grimaces and trembles with frustration when trying—and failing—to communicate. Sometimes, a bit of his professional self reasserts itself and seems to reflect on the cruel absurdity of it all, as during a living-room game of plastic ten-pin bowling with his housemates. "It just struck me" he says, wiping his eyes. "That here we all are, rolling and bowling. It just doesn't make any sense."

Steps To

Enhancing Communication:

INTERACTING WITH PERSONS WITH ALZHEIMER'S DISEASE

A person with Alzheimer's disease often experiences changes in the way he expresses himself and the way he understands others. This brochure offers ways to enhance communication for persons with Alzheimer's and their caregivers.

Communication is the exchange of information, ideas and emotions.

Communication involves the sending and receiving of messages. It is how we relate to one another.

Communication is an important part of our personal relationships. Through communication, we convey our thoughts, wishes and feelings. It helps us express who we are.

Communication is more than talking and listening. It involves attitude, tone of voice, facial expressions, and body language.

CHANGES IN COMMUNICATION

The way in which Alzheimer's disease affects communication will vary with each person. The person with dementia may find it increasingly difficult to express himself in words, and have trouble understanding what has been said. Those who interact with the person may recognize some of the following changes:

- Difficulty finding the right words
- Using familiar words repeatedly
- Inventing new words to describe familiar objects
- Easily losing train of thought
- Difficulty organizing words logically
- Reverting to speaking in a native language
- Using curse words
- Speaking less often
- Relying on nonverbal gestures more often

Keep in mind that a variety of physical conditions and medications can also affect a person's communication. Be sure to check with a physician when you notice significant changes.

HELPING THE PERSON WITH ALZHEIMER'S COMMUNICATE:

YOUR APPROACH TO LISTENING

Communicating with a person affected by Alzheimer's disease requires patience and understanding. First and foremost, you must be a good listener. When helping the person communicate:

Be patient and supportive.

Let him know you're listening and trying to understand what he's saying.

Show your interest.

Maintain eye contact and show him that you care about what he's saying.

Offer comfort and reassurance.

If the person is having difficulty expressing himself, let him know it's all right. Encourage him to continue to explain his thoughts.

Give him time.

Let him think about and describe what he wants. Be careful not to interrupt.

Avoid criticizing or correcting.

Don't tell him what he's saying is incorrect. Rather, listen and try to find meaning in what is being said. Repeat what was said if clarification is needed.

Don't argue.

If the person says something you don't agree with, let it be. Arguing often only makes things worse.

Offer a guess.

If he uses the wrong word or cannot find a word, try helping him out. If you understand what he means, it may not be necessary to provide the correct word. In either case, be careful not to cause unnecessary frustration.

Focus on feelings, not facts.

Sometimes, the emotions being expressed are more important than what is being said. Look for the feelings behind the words. At times, tone of voice and other actions may help you understand how the person is really feeling.

Limit your distractions.

Find a place that is quiet, so that you won't be interrupted and he can focus on his thoughts.

Encourage him to communicate nonverbally.

If you don't understand what he is trying to say, ask him to point or gesture.

HELPING THE PERSON WITH ALZHEIMER'S UNDERSTAND:

YOUR APPROACH TO COMMUNICATING

As Alzheimer's disease progresses, communication can become increasingly challenging. Sensitive, ongoing communication is important, no matter how difficult it may become or how confused the person may appear. Although he may not always respond, he still requires and benefits from continued communication.

When communicating with a person with Alzheimer's, *words* must be chosen carefully. To enhance your interactions, try some of the following techniques:

Identify yourself.

Approach him from the front and tell him who you are.

Address the person by name.

This is not only courteous, but also helps orient him and get his attention.

Use short, simple, familiar words and sentences.

Don't overwhelm him with lengthy requests or stories. Speak concisely and keep to the point. In some cases, slang words may be helpful.

Talk slowly and clearly.

Be aware of speed and clarity when speaking.

Give one-step directions.

Break tasks and instructions into clear, simple steps, giving one step at a time.

Ask one question at a time.

Don't overwhelm or confuse him with too many questions at once.

Patently wait for a response.

He may need some extra time to process your request. Give him the time and encouragement he needs to respond.

Repeat information or questions.

If he doesn't respond, wait a moment and ask again. Use the same phrasing and words as before.

Turn questions into answers.

Try providing the solution, rather than the question. For example, say "The bathroom is right here" instead of asking "Do you need to use the bathroom?"

Avoid literal expressions.

Directions such as, "Hop in!" may be taken literally and cause unnecessary confusion.

Avoid pronouns.

Instead of saying "Here it is," try "Here is your bat."

Emphasize key words.

Stress words that are most important such as, "Here is your coffee."

Make negatives more positive.

Instead of saying, "Don't go there," try saying, "Let's go here."

Give visual cues.

Demonstrate your request by pointing, touching or beginning the task for the person.

Avoid quizzing.

Some reminiscence can be healthy, but avoid asking "Do you remember when...?" or using statements like, "You should know who that is."

Provide simple explanations.

Avoid using logic and reason at great length. Provide thorough responses in a clear and concise way.

Write things down.

Try using written explanations for reminders or when verbal ones seem too confusing.

Try again later.

If he looks like he's not paying attention, try to communicate again a few moments later.

Treat him with dignity and respect.

Avoid talking down to him or talking as if he isn't there.

Also, be aware of the tone you use:

- Speak slowly and distinctly.
- Use a gentle and relaxed tone of voice. A lower voice pitch is more calming.
- Convey an easy going, non-demanding manner of speaking.
- Be aware of your feelings and attitude. They're often communicated, unintentionally, through tone of voice.

Pay special attention to your body language:

- Always approach the person from the front and avoid sudden movements.
- Maintain eye contact.
- Be aware of your stance to avoid sending a negative message.
- Use positive and friendly facial expressions.
- Use nonverbals such as pointing, gesturing and touching.

SPECIAL CONSIDERATIONS

For the Hearing Impaired:

When communicating with someone who is hearing impaired:

- Approach him from the front.
- Stand directly in front of the person when speaking to him.
- Get his attention by saying his name and gently touching him.
- Speak slowly and clearly, and use a lower tone of voice.
- Use nonverbal communication such as pointing or gesturing.
- Write things down if needed.
- If he has a hearing aid, encourage him to wear it and check the battery often.

For the Visually Impaired:

When communicating with someone who is visually impaired:

- Avoid startling him.
- Identify yourself as you approach him.
- Inform him of your intentions before you proceed.
- Use large print or audiotape materials if available.
- Avoid loud noises or sudden movements.
- If he has glasses, encourage him to wear them, keep them clean and check the prescription regularly.

Tips for Better Communication

- Be calm and supportive.
- Focus on feelings, not facts.
- Pay attention to tone of voice.
- Identify yourself and address the person by name.
- Speak slowly and clearly.
- Use short, simple and familiar words.
- Ask one question at a time.
- Allow enough time for a response.
- Avoid the use of pronouns, negative statements and quizzing.
- Use nonverbal communication such as pointing and touching.
- Offer assistance as needed.
- Don't talk about the person as if he wasn't there.
- Have patience, flexibility and understanding.

ALZHEIMER'S ASSOCIATION:
SOMEONE TO STAND BY YOU



The Alzheimer's Association is the only national voluntary organization dedicated to conquering Alzheimer's disease through research and to providing information and support to people with Alzheimer's disease, their families, and caregivers.

Founded in 1980 by family caregivers, the Alzheimer's Association has more than 200 chapters nationwide providing programs and services, including support groups, to assist Alzheimer families in their communities. The Association is the leading funding source for Alzheimer research after the federal government.

Information on Alzheimer's disease, current research, caregiving techniques and assistance for caregivers is available from the Alzheimer's Association. For more information or to locate the chapter nearest you call:

(800) 272-3900

ALZHEIMER'S
ASSOCIATION

Someone to Stand by You

919 North Michigan Avenue
Suite 1000
Chicago, Illinois 60611-1676
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Steps To

Planning

Activities:

STRUCTURING THE DAY AT HOME

A person with Alzheimer's needs help organizing the day. This brochure will guide caregivers in planning activities for the person with Alzheimer's disease.

- ▶ Activities are the "things that we do." These include getting dressed, doing chores, playing cards and even paying bills. They can represent who we are and what we're about.
- ▶ Activities can be active or passive, done alone or in the company of others. They enhance a person's sense of dignity and self-esteem by giving purpose and meaning to his life.
- ▶ Activities structure time and can make the best of retained and existing abilities.
- ▶ Activities can help to lessen undesirable behavior such as wandering or agitation.
- ▶ Activities provide the person with dementia and the caregiver a sense of security, stability, fun and togetherness.

Activities take on many forms and represent different facets of our lives:

Daily Routines:

Personal Care Activities: bathing, shaving and dressing

Mealtime Activities: preparing food, cooking and eating

Chores: dusting, sweeping and doing laundry

Other Activities:

Physical: taking a walk or playing catch

Social: having coffee, talking or playing cards

Intellectual: reading a book or doing a crossword puzzle

Spiritual: praying or singing a hymn

Creative: painting or playing the piano

Work Related: making notes, typing or fixing something

Spontaneous: going out to dinner or visiting friends

When planning activities, think about:

- ▶ *The Person*
- ▶ *The Activity*
- ▶ *Your Approach*
- ▶ *The Environment*

Planning activities for the person with Alzheimer's disease involves continual exploration, experimentation and adjustment. Consider the person's likes and dislikes, strengths and abilities and past interests. As the disease progresses, keep activities flexible and be prepared to make adjustments. Consider the following:

What skills and abilities does the person still have?

The person with Alzheimer's may be able to play simple songs learned on the piano years ago. Incorporate maintained skills into daily activities.

What does the person enjoy?

Note when the person seems happy, anxious, distracted or irritable. Some people with Alzheimer's may enjoy watching sports, while others may be frightened by the fast pace or noise.

Does the person begin activities without direction?

Does the person set the table before dinner or begin sweeping the kitchen floor mid-morning? If so, you may wish to draw upon these types of activities at other times of the day.

Does the person have physical problems?

Does the person tire quickly, have difficulty seeing, hearing or performing simple movements? If so, you may want to avoid certain activities.

Make activities part of your daily routine.

Asking the person with Alzheimer's to help you complete a task—like folding towels—may provide him with a sense of purpose and importance.

Focus on enjoyment, not achievement.

Find activities that build on remaining skills and talents. A professional artist might become frustrated over the declining quality of work, but an amateur might enjoy a new opportunity for self-expression.

Stress involvement.

Activities that help the individual feel like a valued part of the household—like setting the table, wiping countertops or emptying wastebaskets—provide a sense of success and accomplishment.

Relate activity to work life.

A business person might enjoy organization activities such as putting coins in a holder, helping to assemble a mailing, or making a "to do" list. A farmer or gardener would probably enjoy working in the yard.

Look for favorites.

The person who always enjoyed drinking coffee and reading the newspaper may still find that activity enjoyable, even if he's not able to completely comprehend what he's reading.

Modify activities as needed.

Try to be flexible and acknowledge the person's changing interests and abilities.

Consider the time of day.

Many caregivers find they have more success with certain activities such as bathing and dressing in the morning. Whatever the case, your typical daily routine may need to change somewhat.

Adjust activities to stages of the disease.

As the disease progresses, you may want to introduce more repetitive tasks or even expect the person to take a less active role in activities.

Offer support and supervision.

You may need to show the person how to perform the activity and provide simple, step-by-step directions.

Concentrate on the process, not the product.

Does it really matter if the towels are folded properly? Not really. What matters is that you were able to spend time together and the person with Alzheimer's feels as if he has helped do something useful.

Be flexible.

When he insists that he doesn't want to do something, he might be telling you he can't do it or fears doing it. Or if he insists on doing it a different way, let it happen and fix it later.

Be realistic and relaxed.

Don't be concerned about filling every minute of the day with an activity. The person with Alzheimer's needs a balance of activity and rest, and may need more frequent breaks and varied tasks.

Help get the activity started.

Most people with Alzheimer's still have the energy and desire to do things, but lack the ability to organize, plan, initiate and successfully complete the task.

Break activities into simple, easy to follow steps.

Too many directions at once often overwhelm a person with dementia. Focus on one task at a time.

Assist with difficult parts of the task.

If you're cooking, and the person can't measure the ingredients, finish the measuring and say, "Would you please stir this for me?"

Let him know he's needed.

Ask, "Could you please help me?" Be careful, however, not to place too many demands upon the person.

Stress a sense of purpose.

If you ask the person to make a card, he may not respond. But, if you tell him that you're sending a special get-well card to a friend, he may enjoy working on this task with you.

Don't criticize or correct the person.

If the person with Alzheimer's finds a harmless activity that seems significant or meaningful, encourage him to continue.

Encourage self-expression.

Include activities that allow the person a chance to express himself. These types of activities could include painting, drawing, music or conversation.

Involve the person through conversation.

While you're polishing shoes, washing the car, or cooking dinner, talk to the person about what you're doing. Even if the person cannot respond, he is likely to benefit from your communication.

Substitute an activity for a behavior.

If a person with dementia rubs his hand on a table, place a cloth in his hand and encourage him to wipe the table. Or if a person is moving his feet on the floor, play some music so he can tap them to the beat.

Try again later.

If something isn't working, it may be the wrong time of day or the activity may be too complicated. Try again later or adapt the activity.

MAKING A PLAN: STRUCTURING THE DAY

Make activities safe.

Modify a workshop by removing toxic materials and dangerous tools so an activity such as sanding a piece of wood can be safe and pleasurable.

Change your surroundings to encourage activities.

Leave out scrapbooks, photo albums or old magazines that help the person with Alzheimer's reminisce.

Minimize distractions that can frighten or confuse.

The person with Alzheimer's may not be able to recall familiar sounds and places, or may feel uncomfortable in certain settings.

When planning the day for the person with Alzheimer's, think about how you organize your own day.

There are times when you want variety and other times when you welcome routine. The challenge for caregivers is to find activities that provide meaning and purpose, as well as pleasure.

Begin by thinking about the past week. Make notes about activities and experiences that worked and didn't work. Try keeping a daily journal and ask yourself the following questions:

▶ *Which activities worked best and which didn't? Why?*

▶ *Were there times when there was too much going on or too little to do?*

▶ *Were spontaneous activities enjoyable and easily completed?*

Set up a written schedule based on your journal. A patterned day allows you to spend less time and energy trying to figure out what to do from moment to moment. Allow yourself and the person with dementia some flexibility for spontaneous activities.

When structuring the day, consider the following examples of activities:

Morning Activities:

- Wash, brush teeth, get dressed
- Prepare and eat breakfast
- Coffee and conversation
- Discuss newspaper, make a craft or reminisce about old photos
- Take a break or have some quiet time
- Do some chores together
- Take a walk or play an active game

Afternoon Activities:

- Prepare and eat lunch, read mail, clear and wash dishes
- Listen to music, do a crossword puzzle or watch television
- Do some gardening, take a walk or visit a neighbor
- Take a short break or nap

Evening Activities:

- Prepare and eat dinner, and clean up the kitchen
- Reminisce over coffee and dessert
- Play cards, watch a movie or give a massage
- Take a bath, get ready for bed, read a book or look through a magazine

EVALUATING YOUR PLAN: DETERMINING WHICH ACTIVITIES WORK

In evaluating the success of an activity, look at how well the person with Alzheimer's responds and how well the activity meets your needs.

The success of an activity can vary from day to day. In general, if the person seems bored, distracted or irritable, it may be time to introduce another activity or to take time out for rest.

In most cases, structured, pleasant activities decrease agitation and improve mood. The nature of the activity and the degree to which the person completes it successfully are not as important as the pleasure and sense of accomplishment the person derives from it.

Tips For Planning Activities

- Choose activities that bring meaning, purpose, joy and hope to the person's life
- Select activities that use the retained skills and abilities of the person with dementia
- Pick activities that help normalize the person's life
- Choose activities that can involve family and friends
- Look for activities that are dignified and appropriate for adults
- Focus on activities that are enjoyable
- Select activities where the process is more important than the final product

Tips For Your Approach

- Be flexible
- Avoid correcting the person
- Stress involvement
- Be patient
- Help the person remain as independent as possible
- Offer opportunities for choice
- Simplify instructions
- Establish a familiar routine
- Respond to the person's feelings
- Provide encouragement and praise
- Simplify, structure and supervise

ALZHEIMER'S ASSOCIATION: SOMEONE TO STAND BY YOU



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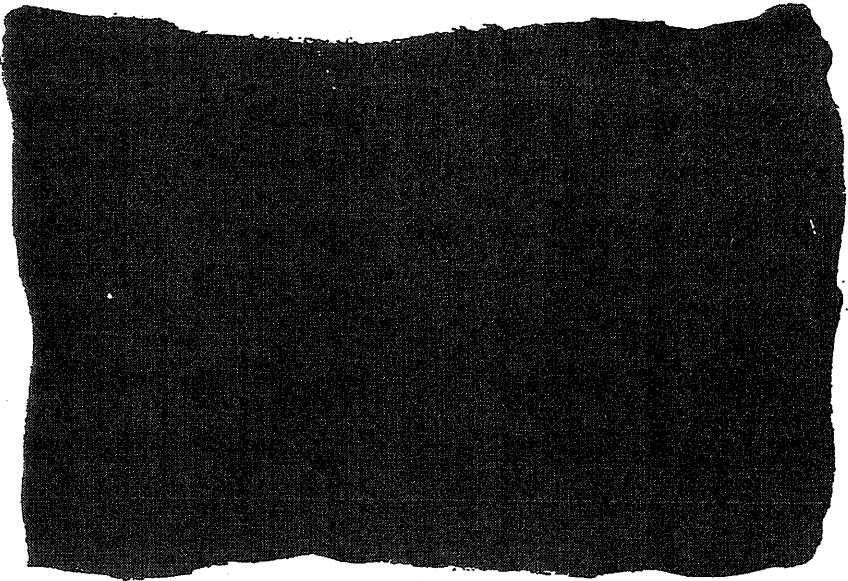


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Women and Alzheimer's Disease.



**A Major Health Issue
for the
Next Millennium.**



Alzheimer's disease is a devastating disease that is rapidly becoming one of the major health issues in America. Currently, there are approximately 4 million Americans who have Alzheimer's disease and as the population ages, the number is expected to reach 14 million by the year 2050.

Although Alzheimer's disease afflicts both sexes, it is a disease that particularly affects women. For one, women are more likely to develop Alzheimer's disease than men. Also, women are much more likely to be a caregiver of someone who has Alzheimer's disease. Presently, there is no cure for Alzheimer's disease, but there are treatments that show signs of hope. Research into the causes of the disease continues at a feverish pace, with the ultimate goal of one day finding a prevention or cure.

This guide is intended to provide you with such valuable information as: warning signs of the disease, treatment options, caregiver tips, and more. Your doctor or other health care professional is also an excellent source of information on Alzheimer's disease.

If you learn someone close to you has been diagnosed with Alzheimer's disease, it's important that you seek the help of others. Help is available. This support can make a big difference in the lives of everyone concerned.

What is Alzheimer's disease?

Alzheimer's is a disease of the brain that causes a steady decline in memory. This results in dementia — a loss of intellectual functions (thinking, remembering, and reasoning) severe enough to interfere with everyday life.

Alzheimer's disease usually begins gradually, causing a person to forget recent events and to have difficulty performing familiar tasks. How rapidly the disease advances varies from person to person, causing confusion, personality and behavior changes, and impaired judgment. Communication becomes difficult as the person with Alzheimer's struggles to find words, finish thoughts, or follow directions. Eventually, persons with Alzheimer's become totally unable to care for themselves.

Women and Alzheimer's disease: A major health issue in the New Millennium.

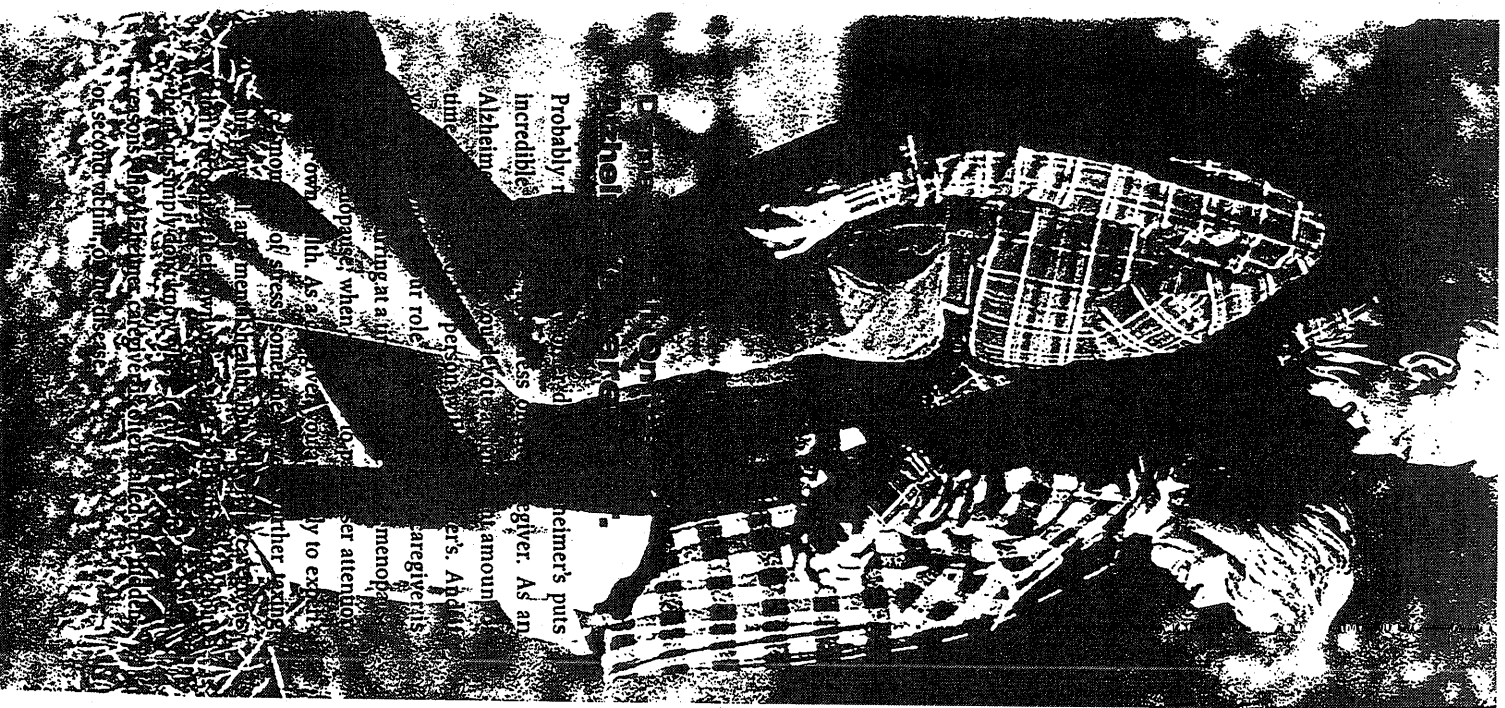
For reasons not yet completely understood, a woman is more likely to contract Alzheimer's disease than is a man. This is largely because, on average, women live longer than men, and the occurrence of Alzheimer's disease greatly increases with age. Alzheimer's disease may be more prevalent in women for reasons we do not understand. Some studies have suggested that estrogen loss during menopause may be a contributing factor, although this has not been proved. More research is still needed to determine whether estrogen replacement therapy (ERT) will prove to be an effective treatment for Alzheimer's disease. Certainly, women — often wives, daughters, and daughters-in-law — constitute the majority of caregivers for those who have the disease.

Common Warning Signs and Symptoms of Alzheimer's disease.

To help you know what warning signs to look for, the Alzheimer's Association has developed a checklist of common symptoms. Review the list and check the symptoms that concern you. If you make several check marks, the individual with the symptoms should see a physician for a complete examination.

- 1. Recent memory loss that affects job skills.**
It's normal to occasionally forget assignments, colleagues' names, or a business associate's telephone number and remember them later. Those with a dementia, such as Alzheimer's disease, may forget things more often and may not remember them later.
- 2. Difficulty performing familiar tasks.**
Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them at the end of the meal. People with Alzheimer's disease could prepare a meal and not only forget to serve it, but also forget they made it.

- 3. Problems with language.**
Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute inappropriate words, making sentences incomprehensible.
- 4. Disorientation of time and place.**
It's normal to forget the day of the week or a destination for a moment. But people with Alzheimer's disease can become lost on their own street, not knowing where they are, how they got there, or how to get back home.
- 5. Poor or decreased judgment.**
For most people, becoming immersed in an activity can make them temporarily forget the child they're watching. But a person who has Alzheimer's disease can forget entirely that there is a child under their care.
- 6. Problems with abstract thinking.**
Balancing a checkbook may be disconcerting when the task is more complicated than usual. Someone with Alzheimer's disease could forget completely what the numbers are and what needs to be done with them.
- 7. Misplacing things.**
Anyone can temporarily misplace his or her wallet or keys. A person with Alzheimer's disease may put things in inappropriate places: an iron in the freezer or a wristwatch in the sugar bowl.
- 8. Changes in personality and behavior.**
People's personalities ordinarily change with age. But a person with Alzheimer's disease can change drastically, becoming extremely confused, suspicious, or fearful. Alzheimer's disease can also affect a person's behavior, producing rapid mood swings — from calm to tears to anger — for no apparent reason.
- 9. Loss of initiative.**
It's normal to tire of housework, business activities, or social obligations, but most people regain their initiative. The person with Alzheimer's disease may become very passive and require cues and prompting to become involved.



10 Signs of Caregiver Stress.

Too much stress can be damaging to you and the person for whom you are caring. The following stress indicators, experienced frequently or simultaneously, can lead to more serious health problems. Learn to recognize signs of stress in yourself. Taking care of yourself will help you be a better caregiver.

1. **Denial** about the disease and its effect on the person who's been diagnosed. *"I know mom's going to get better."*
 2. **Anger** at the person with Alzheimer's or others; that no effective treatments or cures currently exist; and that people don't understand what's going on. *"If he asks that question one more time I'll scream!"*
 3. **Social withdrawal** from friends and activities that once brought pleasure. *"I don't care about getting together with the neighbors anymore."*
 4. **Anxiety** about facing another day and what the future holds. *"What happens when he needs more care than I can provide?"*
 5. **Depression** begins to break your spirit and affects your ability to cope. *"I don't care anymore."*
 6. **Exhaustion** makes it nearly impossible to complete necessary daily tasks. *"I'm too tired for this."*
 7. **Sleeplessness** caused by a never-ending list of concerns. *"What if she wanders out of the house or falls and hurts herself?"*
 8. **Irritability** leads to moodiness and triggers negative responses and reactions. *"Leave me alone!"*
 9. **Lack of concentration** makes it difficult to perform familiar tasks. *"I was so busy, I forgot we had an appointment."*
 10. **Health problems** begin to take their toll, mentally and physically. *"I can't remember the last time I felt good."*
- If you experience several of these stress symptoms on a regular basis, consult a physician and use the following steps to help manage the stress in your life.

8 Ways to Help Reduce Caregiver Stress.

There's no denying that caring for someone who has Alzheimer's disease is a stressful responsibility. But there are ways to manage this stress and to ensure that, as a caregiver, you remain physically and mentally healthy.

1. **Get a diagnosis as early as possible.** Symptoms of Alzheimer's may appear gradually, and if a person appears physically healthy, it's easy to ignore unusual behavior, or attribute it to something else. If Alzheimer warning signs appear in someone close to you, see a physician as soon as possible.
2. **Know what resources are available.** For your own well-being and that of the person for whom you are caring, become familiar with Alzheimer care resources available in your community. Adult day care, in-house assistance, visiting nurses, and Meals-on-Wheels are just some of the community services that can help. Your local Alzheimer's Association chapter is a good place to start.
3. **Get help.** Trying to do everything by yourself will leave you exhausted. The support of family, friends, and community resources can be an enormous help. If stress becomes overwhelming, don't be afraid to seek professional help. Alzheimer's Association support group meetings and Helplines are also a good source of comfort and reassurance.
4. **Take care of yourself.** Frequently, caregivers totally devote themselves to those for whom they care, and in the process, neglect their own needs. Pay attention to yourself. Watch your diet, exercise, and get plenty of rest. It's also good practice to take time off for shopping, a movie, or a visit with a friend.
5. **Accept changes as they occur.** People with Alzheimer's change, and so do their needs. They often require care beyond what you can provide at home. A thorough investigation of available care options should make transitions easier.

6. Do legal and financial planning.

Consult an attorney and discuss issues related to durable power of attorney, living wills and trusts, future medical care, housing, and other key considerations. Planning now will alleviate stress later.

7. Be realistic.

Until a cure is found, the progression of Alzheimer's disease is inevitable. The care you provide *does* make a difference to your loved one's safety, comfort, health, and well-being. Keep in mind that neither you nor the person with Alzheimer's disease can control many of the circumstances and behaviors that will occur.

8. Give yourself credit, not guilt.

You're only human. Occasionally, you may lose patience and at times, be unable to provide all of the care the way you'd like. Remember, you're doing the best you can, so give yourself credit.

Women Have Reason for Hope.

Current treatments that show promise.

Drug treatments are available from your physician that may temporarily improve symptoms and behaviors related to Alzheimer's disease. Recent studies suggest that nonsteroidal anti-inflammatory drugs (NSAIDs) and vitamin E may offer some protection to nerve cells in the brain. Some preliminary studies have suggested that other medications, such as ERT, may make it possible to delay onset of disease symptoms.

The advantages of these treatment options are that they are available now; the side effects are known and can be managed; and they provide other health benefits for women. ERT, for example, provides relief of menopausal symptoms, like hot flashes and night sweats, as well as reducing the risk of osteoporosis and heart disease. However, more research needs to be done to determine the effectiveness of these treatments for Alzheimer's disease.

Women's Health Initiative Memory Study (WHIMS) — the next big step in Alzheimer's disease research.

Research on estrogen as a preventive treatment for Alzheimer's disease is also underway. The Women's Health Initiative Memory Study (WHIMS) is a large independently funded study created to evaluate the role of ERT and/or hormone replacement therapy (HRT) in the prevention and treatment of Alzheimer's disease. Findings from this study should provide valuable insights into more effective treatments for women who are at risk for Alzheimer's disease.

The National Institutes of Health Women's Health Initiative (WHI).

WHI has been created to develop scientific knowledge about prevention and treatment of diseases common in or unique to women, including Alzheimer's disease, heart disease, breast cancer, colorectal cancer, and osteoporosis. A better understanding of these diseases will undoubtedly lead to more effective treatments that can improve the quality of life for every woman.

The Reagan Institute Initiative.

The Alzheimer's Association formed the Ronald & Nancy Reagan Research Institute to accelerate research, slow the progression of the disease, and reduce the number of people afflicted with Alzheimer's disease. In addition to determining the causes of Alzheimer's disease, one of the Institute's main objectives is to develop safe and effective treatments that will help people with Alzheimer's disease continue to function independently.

The Alzheimer's Association: Someone to Stand by You.

The Alzheimer's Association is the only national voluntary organization dedicated to conquering Alzheimer's disease through research and to providing information and support to people with Alzheimer's disease and their families. The Alzheimer's Association has more than 200 chapters nationwide to assist Alzheimer families in their communities. The Association is the leading funding source for Alzheimer research after the federal government. Information on Alzheimer's disease, current research, patient care, and assistance for caregivers is available from the Alzheimer's Association.



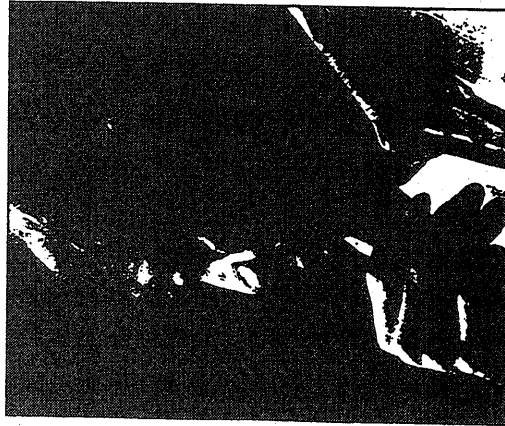
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SIT ALZHEIMERS?



WARNING SIGNS
YOU SHOULD
KNOW

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Someone to Stand By You

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Founded in 1980 by dedicated family members, the Alzheimer's Association today works through a network of more than 220 local chapters, 2,000 support groups, and 35,000 volunteers. The group is officially known as the Alzheimer's Disease and Related Disorders Association.

The Alzheimer's Association is a major source of funding for Alzheimer's research. It is leading the way in defining and implementing quality of care guidelines for dementia patients. And it provides a wide range of programs and services to support patients and their families.

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ALZHEIMER'S ASSOCIATION
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Your wife always misplaces her keys. But last Tuesday, she couldn't remember what they were for.

Your grandfather likes to take daily strolls around the neighborhood. But four times in the past month he's gotten lost and couldn't find his way home without help from a neighbor.

Your favorite uncle can't remember your name or the names of your husband or children.

The memory loss, confusion, and disorientation described in these examples are symptoms of dementing illness. The most common dementing illness is Alzheimer's disease.

Unfortunately, many people fail to recognize that these symptoms indicate something is wrong. They may mistakenly assume that such behavior is a normal part of the aging process; it isn't. Or, symptoms may develop gradually and go unnoticed for a long time. Sometimes people refuse to act even when they know something's wrong.

It's important to see a physician when you recognize these symptoms. Only a physician can properly diagnose the person's condition, and sometimes symptoms are reversible. Even if the diagnosis is Alzheimer's disease, help is available to learn how to care for a person with dementia and where to find assistance for yourself, the caregiver.

THE FIRST STEP, THOUGH, IS TO LEARN MORE
ABOUT ALZHEIMER'S DISEASE.

To help you know what warning signs to look for, the Alzheimer's Association has developed a checklist of common symptoms (some of them also may apply to other dementing illnesses). Review the list and check the symptoms that concern you. If you make several check marks, the individual with the symptoms should see a physician for a complete examination.

RECENT MEMORY LOSS THAT AFFECTS JOB SKILLS

It's normal to occasionally forget assignments, colleagues' names, or a business associate's telephone number and remember them later. Those with a dementia, such as Alzheimer's disease, may forget things more often, and not remember them later.

DIFFICULTY PERFORMING FAMILIAR TASKS

Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them at the end of the meal. People with Alzheimer's disease could prepare a meal and not only forget to serve it, but also forget they made it.

PROBLEMS WITH LANGUAGE

Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute inappropriate words, making his or her sentence incomprehensible.

DISORIENTATION OF TIME AND PLACE

It's normal to forget the day of the week or your destination for a moment. But people with Alzheimer's disease can become lost on their own street, not knowing where they are, how they got there or how to get back home.

POOR OR DECREASED JUDGMENT

People can become so immersed in an activity that they temporarily forget the child they're watching. People with Alzheimer's disease could forget entirely the child under their care. They may also dress inappropriately, wearing several shirts or blouses.

PROBLEMS WITH ABSTRACT THINKING

Balancing a checkbook may be disconcerting when the task is more complicated than usual. Someone with Alzheimer's disease could forget completely what the numbers are and what needs to be done with them.

MISPLACING THINGS

Anyone can temporarily misplace a wallet or keys. A person with Alzheimer's disease may put things in inappropriate places: an iron in the freezer, or a wristwatch in the sugar bowl.

CHANGES IN MOOD OR BEHAVIOR

Everyone becomes sad or moody from time to time. Someone with Alzheimer's disease can exhibit rapid mood swings—from calm to tears to anger—for no apparent reason.

CHANGES IN PERSONALITY

People's personalities ordinarily change somewhat with age. But a person with Alzheimer's disease can change drastically, becoming extremely confused, suspicious, or fearful.

LOSS OF INITIATIVE

It's normal to tire of housework, business activities, or social obligations, but most people regain their initiative. The person with Alzheimer's disease may become very passive and require cues and prompting to become involved.

This section answers some of the most frequently asked questions about Alzheimer's disease.

Q: What is Alzheimer's disease?

A: Alzheimer's disease is a progressive, degenerative disease of the brain in which brain cells die and are not replaced. It results in impaired memory, thinking, and behavior, and is the most common form of dementing illness.

Q: What are other causes of Alzheimer-like symptoms?

A: Depression, nutritional deficiencies, drug interaction or intoxication, and thyroid imbalances can cause symptoms similar to those related to Alzheimer's disease, and sometimes these symptoms are reversible with a physician's care. Symptoms are also found with dementias associated with stroke, Huntington's disease, Parkinson's disease, Pick's disease, and AIDS.

Q: How prevalent is the disease?

A: An estimated 4 million Americans are afflicted with Alzheimer's disease. It is the fourth leading cause of death among American adults. Because the population is aging, an estimated 14 million will have the disease by the year 2050.

Q: Who is afflicted with Alzheimer's disease?

A: Ten percent of those over 65, and almost

half of those over age 85 have the disease. However, because of improved testing and greater public awareness, physicians are seeing an increase in diagnosed patients in their 40s and 50s. Alzheimer's disease strikes equally at men and women, all races, and all socioeconomic groups.

Q: What causes Alzheimer's disease?

A: The causes of Alzheimer's disease are still unknown, and there currently is no cure.

Q: What should I do if I have noticed these symptoms in a loved one?

A: Make an appointment with a physician for a complete examination. Discuss the symptoms you've noticed and your concerns. Your physician may refer you to a neurologist for additional testing.

Q: How is Alzheimer's disease diagnosed?

A: A definitive diagnosis of Alzheimer's disease is only possible with an autopsy. However, there has been enormous progress in diagnostic testing in recent years, leading to 80- to 90-percent accurate diagnoses of Alzheimer's by physicians. There is no single, or simple test to diagnose Alzheimer's disease. A detailed medical history and physical examination are done. Then a series of neurological tests may be conducted over a period of time. The process is intended to rule out any other possible cause of symptoms.



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What is Alzheimer's disease?

What causes Alzheimer's disease?

Scientists are still not certain what causes the disease. Age and family history with Alzheimer's disease are identifiable risk factors for the disease. Scientists are exploring the role of genetics in the development of Alzheimer's, focusing on chromosome 19. (Rarer forms of the disease, which strike people in their 30s and 40s, often run within families and appear to be related to chromosome 1, chromosome 14, and chromosome 21.) Many researchers and physicians are coming to believe that Alzheimer's is a complex disease, probably caused by a variety of influences.

Does Alzheimer's disease run in families?

The evidence is not clear: Cases where several members of a single family have had autopsy-confirmed diagnoses of Alzheimer's disease are rare. Much more common is the situation where a single family member is diagnosed as having probable Alzheimer's (meaning that physicians are 80 to 90 percent certain that it is Alzheimer's).

A person's risk of developing the disease seems to be slightly higher if a first-degree relative (brother, sister, parent) has the disease. This situation is called "familial," which means there could be a genetic factor involved, or perhaps family members were exposed to something in the environment that caused the disease.

Alzheimer's is a disease of the brain that causes a steady decline in memory. This results in dementia - loss of intellectual functions (thinking, remembering, and reasoning) severe enough to interfere with everyday life.

When German physician Alois Alzheimer first described the disease in 1907, it was considered rare. Today, Alzheimer's disease is the most common cause of dementia, affecting 10 percent of people 65 years old, and nearly 50 percent of those age 85 or older. An estimated 4 million Americans have Alzheimer's.

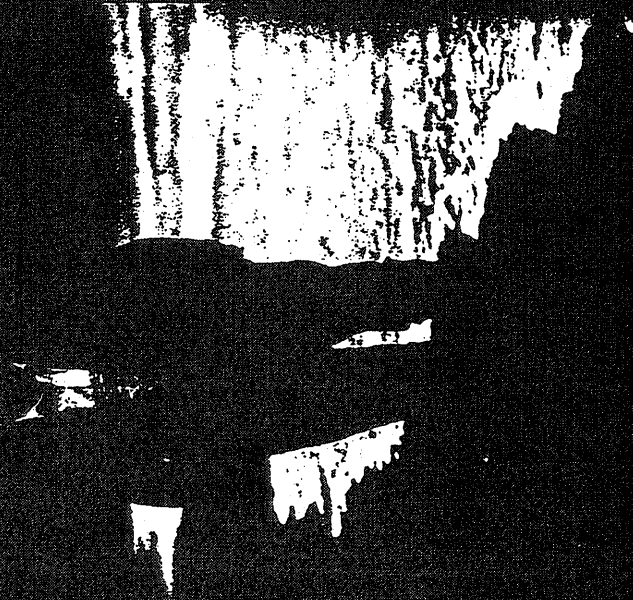
Alzheimer's disease usually begins gradually, causing a person to forget recent events and to have difficulty performing familiar tasks. How rapidly the disease advances varies from person to person, causing confusion, personality and behavior changes, and impaired judgment. Communication becomes difficult as the person with Alzheimer's struggles to find words, finish thoughts, or follow directions. Eventually, persons with Alzheimer's become totally unable to care for themselves.

SERIES

An Overview of Alzheimer's Disease and Related Dementias

ALZHEIMER'S
ASSOCIATION

Someone to Stand by You



Does Alzheimer's disease occur in younger adults?

Yes. The disease can occur in people in their 30s, 40s and 50s, however, most people diagnosed with Alzheimer's are older than age 65. This is called "early-onset" and represents less than 10 percent of Alzheimer cases. When a younger adult has Alzheimer's disease, the issues related to care, financial planning, work, family, children, etc., can be very different than with older adults with the disease.

What is the difference between Alzheimer's disease and normal age-related memory difficulties?

Activity

Person	A Person with Alzheimer's Disease	A Person with Age-Associated Memory Problems
Remembers later	rarely	often
Can follow written or spoken directions	gradually unable	usually able
Can use notes	gradually unable	usually able
Can care for self	gradually unable	usually able

NOTE: Determination of whether memory loss is associated with Alzheimer's disease can only be made by health care professionals.

Isn't memory loss a natural part of aging?

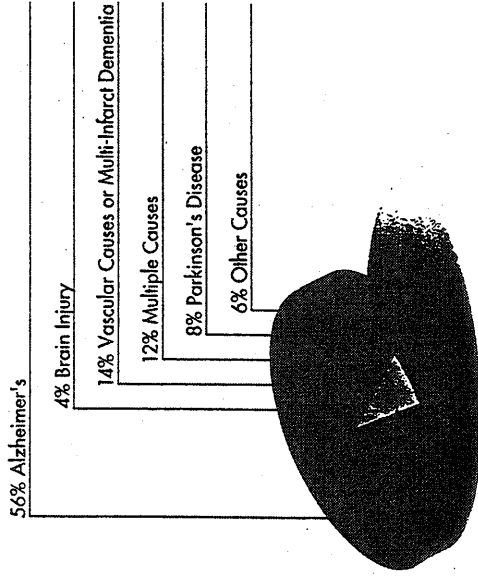
Yes and no. Everyone has forgotten where they parked the car or the name of an acquaintance at one time or another. And many healthy individuals are less able to remember certain kinds of information as they get older.

The symptoms of Alzheimer's disease are much more severe than such simple memory lapses. Alzheimer symptoms affect communication, learning, thinking, reasoning, and can have an impact on a person's work and social life.

The chart below provides examples of the differences between persons with Alzheimer's disease and age-related memory problems.

What other diseases act like Alzheimer's?
Many conditions can cause dementia. Dementia related to depression, drug interaction, thyroid and other problems may be reversible if detected early. It is important to identify the actual cause in order to receive proper care. Alzheimer's disease is the leading cause of dementia, as the graph below shows.

Causes of Dementia



Some of the other diseases that cause dementia are:

Creutzfeldt-Jakob disease (CJD) - a rare, fatal brain disease caused by infection. Symptoms are failing memory, changes in behavior and lack of muscular coordination. CJD progresses rapidly, usually causing death within a year. No treatment is currently available.

Multi-infarct dementia (MID) - also known as vascular dementia, results from brain damage caused by multiple strokes (infarcts) within the brain. Symptoms can include disorientation, confusion and behavioral changes. MID is neither reversible nor curable, but treatment of underlying conditions (e.g., high blood pressure) may halt progression.

Normal pressure hydrocephalus (NPH) -

a rare disease caused by an obstruction in the flow of spinal fluid. Symptoms include difficulty in walking, memory loss and incontinence. NPH may be related to a history of meningitis, encephalitis, or brain injury, and is often correctable with surgery.

Pick's disease - a rare brain disease that closely resembles Alzheimer's, with personality changes and disorientation that may precede memory loss. As with Alzheimer's disease, diagnosis is difficult, and can only be confirmed by autopsy.

Parkinson's disease - a disease affecting control of muscle activity, resulting in tremors, stiffness and speech impediment. In late stages, dementia can occur, including Alzheimer's disease. Parkinson drugs can improve steadiness and control, but have no effect on mental deterioration.

Lewy body disease - a disease, recognized only in recent years, in which the symptoms are a combination of Alzheimer's disease and Parkinson's disease. Usually, dementia symptoms are initially present followed by the abnormal movements associated with Parkinson's. There is no treatment currently available.

Huntington's disease - a hereditary disorder characterized by irregular movements of the limbs and facial muscles, a decline in thinking ability, and personality changes. In contrast to Alzheimer's, Huntington's can be positively diagnosed and its movement disorders and psychiatric symptoms controlled with drugs. The progressive nature of the disease cannot be stopped.

Depression - a psychiatric condition marked by sadness, inactivity, difficulty with thinking and concentration, feelings of hopelessness, and, in some cases, suicidal tendencies. Many severely depressed persons also display symptoms of memory loss. Depression can often be reversed with treatment.

How is Alzheimer's disease diagnosed?

There is no single diagnostic test. Instead, Alzheimer's disease is diagnosed through process of elimination - to rule out other diseases and conditions that can also cause dementia. Whether conducted by a family physician or a team of specialists, the process usually involves the following:

- A thorough medical history of the person with symptoms of Alzheimer's as well as family members
- An assessment of the person's mental status
- A thorough physical exam
- A neurological exam
- A series of lab tests
- Psychological and other exams

A diagnosis of Alzheimer's disease obtained through this evaluation is considered 80 to 90 percent accurate. The only way to be absolutely certain the person has Alzheimer's is through an autopsy.

What treatment is available?

There is no medical treatment at this time to cure or stop the progression of Alzheimer's disease. Two drugs approved by the FDA - tacrine (also known as Cognex™) and donepezil hydrochloride (also known as Aricept™) - may temporarily improve symptoms related to the disease.

In addition, many promising new drugs are now being studied to find out whether they can slow the progression of the disease or improve memory. To learn more about current clinical drug trials, contact the Alzheimer's Association at (800) 272-3900.

Medications are also available to reduce some of the behavioral symptoms associated with Alzheimer's, such as depression, sleeplessness and agitation.



What else can be done?

Learn how the Alzheimer's Association can help.

The Alzheimer's Association has a network of more than 200 chapters nationwide, providing programs and services within their communities that assist persons with Alzheimer's disease, their families and caregivers. These programs and services include support groups, telephone helplines, educational seminars, and a variety of publications on the disease, on current research, caregiving approaches and more.

The Alzheimer's Association is the only national voluntary health organization dedicated to conquering Alzheimer's disease through research, and to providing education, support and advocacy for people with Alzheimer's disease, their families and caregivers. For more information or to contact the chapter nearest you, call:

(800) 272-3900

or email: info@alz.org

What additional resources are available?

The following resource materials are available from your local chapter or the national office of the Alzheimer's Association:

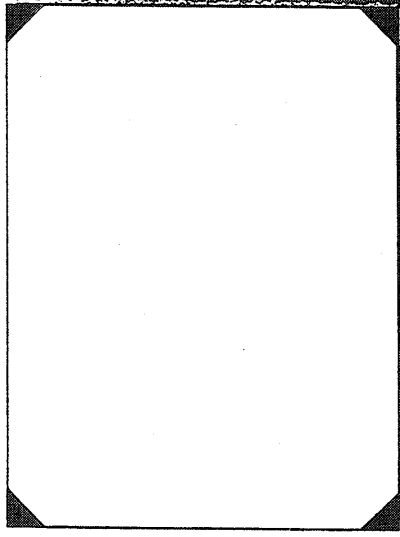
- ▶ *Is it Alzheimer's? Warning Signs You Should Know*
- ▶ *Steps to Getting a Diagnosis: Finding Out if It's Alzheimer's Disease*
- ▶ *Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease*
- ▶ *Steps to Understanding Challenging Behaviors: Responding to Persons with Alzheimer's Disease*
- ▶ *Steps to Planning Activities: Structuring the Day at Home*
- ▶ *Steps to Understanding Legal Issues: Planning for the Future*
- ▶ *Steps to Enhancing Your Home: Modifying the Environment*
- ▶ *Caregiver Stress: Signs to Watch For, Steps to Take*
- ▶ *The 36-Hour Day: A Guide to Caring for Persons with Alzheimer's Disease and Related Dementing Illnesses* by Nance L. Mace and Peter V. Rabins, M.D. Baltimore: Johns Hopkins University Press, 1991 (revised edition)
- ▶ *Drug Fact Sheets*



Someone to Stand by You

919 North Michigan Avenue
Suite 1000
Chicago, IL 60611-1676
1-800-272-3900
TDD: (312) 355-8882
<http://www.alz.org>
email: info@alz.org

Contact the chapter nearest you.



ED205Z

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DR. NEIL E. PETERSON & ASSOCIATES

5019 W. NORTH AVENUE
MILWAUKEE, WI 53208
414-445-6600

My name is Neil E. Peterson. I'm a Pediatric dentist and I practice at 50th and North Avenue in Milwaukee. The great majority of my patients are children on Title 19, most of them in HMO's.

About a month ago I read an article in the Sunday Milwaukee Journal Sentinel that stated cavities were becoming a thing of the past. (Enclosed.) That may be true in the suburbs but where I work there seems to be a dental caries epidemic. It is often the norm to see a child with 20 primary teeth and 8-12 cavities. Problems you wouldn't believe unless you saw it... abscessed teeth, painfully decayed teeth and bleeding gums. Emergency visits are common. Nursing Bottle caries are common place. Dental disease is running rampant and that is NO exaggeration!

Many offices and dentists refer children to me because they don't take Title 19 or because the complexity of treatment and need for behavior management requires specialty care. My schedule is booked up far in advance and the end seems no where in sight. Young Pediatric dentists shy away from this type of practice because the compensation is so low and the stress level so high. I'm fortunate to have a well trained staff to help me some with 25+ years experience.

I've been located here for almost 30 years and I've grown to care deeply for these children. Years ago when the first HMO - Totalcare - was formed, all the pediatric dentists on the staff at Childrens Hospital of Wisconsin were providers. As funds for dentistry were fractioned off by HMO plans that followed Totalcare, the providers dropped out. Why should 40% of the capitation dollars go to "administration" by an insurance company? I know for a fact that the dental IPA was run for 11¢ per patient in the early 1990's. That's when we did it ourselves!

Who knows if all the effort expended at my office is ever going to make a difference? The child with the greatest need receive the lowest funding. Unless increases can be provided for Title 19 dentistry and the middle men cut out of the HMO plans, only a very few dentists like me will continue as providers. I'm beginning to think of retirement or at least slowing down. I joke at the office that "this job would kill an ordinary man" but its not really a joke. The office operates like a MASH unit and we've all experienced burn out.

Now I understand that a card reader is required to identify recipients - \$600 at my expense and another 30¢ each time a patient I.D. card is run through the card reader-also at my expense.

If the capitation rate is around \$3 and the Insurance HMO takes 35-40% and the IPA another 10% and the card reader 10%, whats left to care for the child? It makes me wonder if I'm a humanitarian or a fool. Maybe if we all quit someone at the top would see the light. I'm sorry I can't be available to testify in person - but Thursdays are very busy and I'm scheduled ahead well in August, September, and October. Enclosed is a copy of my schedule for Thursday April 8, 1999. It's a free day from school and we're doing as many check-ups as we can. I've called in extra staff to be ready but 1/2 these phone numbers are disconnected and our show rate will likely be about 45%. We have to overbook to compensate. Thank you for your consideration of these problems which are specific to the Title 19 dental plan.

Neil E Peterson DDS 4-7-99

The whole tooth

Dentists say we are nearing advent of a 'cavity-free society'

By NEIL D. ROSENBERG
of the Journal Sentinel staff

Chicago — America is on the verge of wiping out dental cavities, according to the nation's top dental official.

A child born in 1999 in the United States who has access to decent dental care will likely grow into adulthood free of cavities, said Harold C. Slavkin, director of the National Institutes of Health's National Institute of Dental Research. He spoke Friday between sessions of the Chicago Dental Society's annual meeting, which attracted more

than 10,000 dentists, dental assistants and hygienists.

Even now, 85% of U.S. youngsters ages 5 through 17 are cavity-free, more than twice the 26% no-cavity rate in 1974, according to data from the dental research institute. In fact, Slavkin said, 80% of all cavities in this age group are in only 20% of youngsters, typically the poor and others with limited access to dental care.

Slavkin's own four children, ages 31 to 37, are the prototype. "None of my children ever had a cavity," he said.

Please see TBETH page 10

Today we called 23 Pediatric dentists listed in the Milwaukee yellow pages:

- 17 dentists took no Title 19 at all
- 4 dentists would except some straight Title 19
- 2 dentists limited participation to some HMO's

THURSDAY APRIL 8, 1999

SPRING RECESS

DR. PETERSON/ HYGIENE DAY!!

HYGIENE

8:30	Dyadmond CHS HYG. Lakisha CHS HYG. 9:00 Markell CHS HYG. Thomas CHS HYG. Clairene P HYG.	<i>Catrina XIX</i>	8:30	Marissa PC Aciana CHS
9:30	Ossie CHS HYG. 10:00 Shakia PC HYG. Candice PC HYG. Jahmiya I HYG.	<i>Jameral XIX</i>	9:00	Aaron XIX Niyah I Lavance PC Alfonzo P. Demario CHS Demetrius CHS
10:00	Joseph PC N HYG. Kaderja CHS N HYG.		10:00	Terrence PC Don PC
10:30	Darnell CHS N HYG. 10:00 Michael WHO N HYG. Jeremy PC N HYG. <i>Austin</i> Taurean PC N HYG. <i>RKS</i>		10:30	Latoya PC Racquel CHS Lance WHO Cocoa WHO Luciano MXC
11:00	Donovon PC N HYG.		11:00	Herbert MXC N
1:00	Alicia N XIX HYG. Dorothy PC HYG. 1:00 Allen CHS N HYG.	<i>Arianne CHS</i>	1:00	Deangelo PC Carmen XIX Brittany XIX Nesby PC N Curtis XIX Isiah PC
1:30	Frank PC N HYG. Aalyah MHS HYG. Joshua XIX HYG. Kenneth XIX HYG. Anthony MHS HYG. Azince MHS HYG.		1:30	Montae I Montia I Eleane I Courtney I N
2:00	Sonya PC HYG. Teahara PC HYG. Marquita WHO HYG. LaDraya PC HYG.		2:00	Cqumi:PC: Iesha PC Shyron PC Rebecca PC
2:30	Craig WHO HYG. Jocqites WHO HYG.		2:30	Coniasha WHO N Charles XIX N
3:00	Tavares PC HYG.		3:00	Tiera PC Abram WHO
3:30 <i>2:00</i>	Marquitis WHO HYG. Ralphail PC HYG. K.L. OP PC HYG.		3:00	Lucy WHO Jovan MXC Eric I Erica I Kiana I
4:00	Angelo PC HYG. Lemonica WHO HYG. Juarl Jr. N CHS HYG.		4:00	
9:30	<i>Relo WHO OP PER NEP</i>		9:30	Joseph I
			3:30	<i>Erica I Corey I Andree I</i>

THURSDAY APRIL 8, 1999



NORTHWEST GENERAL HOSPITAL

5310 WEST CAPITOL DRIVE • MILWAUKEE, WISCONSIN 53216 • 414 / 447-8543

April 8, 1999

Dear Joint Finance Committee Members:

I am writing to you today on behalf of Northwest General Hospital to alert you to some serious concerns we have with the 1999-2001 state budget as currently proposed.

Northwest General Hospital is a not-for-profit facility located in Milwaukee and serving the northwest area of the inner city. In addition to acute inpatient services, Northwest General Hospital also provides outpatient services, alcohol and drug abuse inpatient and outpatient services, pre-natal care coordination services, and child care coordination services.

The budget, as currently proposed, will have some far-reaching implications for health care in our state and our communities. Because you may not be aware of its total impact, I am providing you with our assessment of its provision:

The budget proposes to freeze medical assistance rates for care provided in Wisconsin hospitals for the biennium. A small 1% increase in outpatient rates is provided in the second year. The budget also begins the first two years of a process to cut back on the state's financial support for training the physicians Wisconsin will need in the future.

Both of these proposals are troubling for a number of reasons:

1. Wisconsin is purposefully foregoing almost \$14 million federal dollars that could be brought into our state to support health care. The medical assistance base rate freeze and medical education cuts mean that not only will the state's commitment of general purpose dollars be lost, but so will the federal matching funds. For each 40 cents committed by the state to medical assistance programs, 60 cents is funded by the federal government, which translates into a loss of almost \$14 million dollars in federal dollars.
2. The medical assistance funding issue is playing out at the same time Wisconsin hospitals and health systems are bracing for huge cuts in Medicare payments under the Balanced Budget Act of 1997. These cuts began in fiscal year 1999 and will play out through fiscal year 2002. Over that time frame, this will result in cuts of around \$770 million dollars. Over the state's biennium alone, Medicare is projected to take about \$347 million dollars out of Wisconsin's health care system.

For Northwest General Hospital, the combined effect of the freezes and cuts imposed by these two programs on our bottom line over the biennium is \$860,448 dollars, which is a substantial amount of money for our hospital.

3. Cuts of this magnitude will have troubling implications for our community. They cannot simply be absorbed through "becoming more efficient." (It should be noted that, based on federal Medicare data, Wisconsin health care providers are already some of the most efficient in the country.)

These cuts can only be dealt with in one of two ways:

- a) eliminate or reduce needed services to the community such as the very needed Child Care Coordination and Alcohol and Drug Abuse services, to mention only a few, or
- b) shift costs to individual patients or employers who provide and pay for health insurance coverage for their employees

Currently, almost \$80 million dollars in medical assistance payment shortfalls alone are shifted to the private sector annually. This budget proposal will increase that number to about \$88 million dollars in the first year of the biennium and about \$93 million dollars in the second year.

4. These cuts come at a time when health care, like other industries in Wisconsin, is finding it difficult to recruit and retain qualified personnel to serve our patients.

Currently at Northwest General Hospital, the following job categories fall victim to vacancies, recruiting challenges, and turnover: Nurse Anesthetist, Certified Nursing Assistant, Dietary Aide, Dietetic Technician, Nursing Secretary, Medical Technologist, Radiologic Technologist, Pharmacist, Admitting Clerks, RNs, and LPNs.

A freeze in medical assistance rates make it difficult, if not impossible, to give our staff even a cost of living increase, much less make it an attractive place to work for new employees.

5. Finally, there is an element in the budget on which we need your help and which does not have financial implications for the state. The current statutory requirements on criminal background checks have taken a concept that has some merit and turned it into a quagmire.

For example, we have lost good applicants who have not been willing to go through the cumbersome "Rehabilitation Review" process and have elected to work in other industries. Some applicants have simply been overwhelmed with the requirement of the review process, despite having limited patient contact. Long term employees who have exemplary employment records, who have committed crimes in their youth, are subject to banishment from our industry.

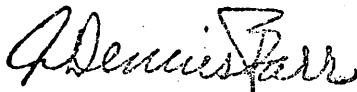
Many employees are living in fear that minor records in the past will result in their dismissal despite our assurance to the contrary. Some, I believe, have left the industry rather than go through the process. Hardest hit are those individuals who work in Alcohol and Drug Treatment. For many years, we have derived some of our best counselors from the ranks of recovered alcohol and drug users. This group, because of their illness, has a much higher incidence of involvement with the law, and hence, is much more vulnerable to the provisions of this law.

We respectfully request that you support the following:

- a) an inflationary increase of 2.4% in the first year and 2.6% in the second year for medical assistance hospital inpatient and outpatient rates (\$7.1 million GPR);
- b) restoration of the medical assistance funding for medical education (\$2.5 million GPR);
- c) the \$2.4 million dollars in the proposed budget to fund a medical assistance supplement, which is designed to assist those providers experiencing increases in charity care due to welfare reform; and
- d) adoption of a reasonable set of requirements for hospitals and nursing homes to perform criminal background checks on employees

Thank you very much for the opportunity to share some of our thoughts with you today. These are important issues to consider in maintaining a quality health care system in Wisconsin, something I'm certain we all want to accomplish.

Sincerely,



C. Dennis Barr
President/CEO

CDB/jdf

Thank you Representative Gard and Senator Burke for allowing me a chance to speak before this committee today. My name is Paul Levine and I practice general dentistry in Milwaukee, Wisconsin. I am honored to practice this esteemed profession with my father and we have a staff of 6 working with us. The goal of our well-trained caring staff and myself is to help people obtain their optimal dental health.

I would like to take this opportunity to speak in favor of portions of the Governor's budget bill as it relates to the Medicaid Program and dentistry. However due to the extensive problems that exist with this governmental program I ask that you not stop with this short term Band-Aid. Why this short term fix is a start, if the program is not looked at and fixed we will face a crisis more major than the access to care issue we now face in just a few short years.

During 1998 I had the opportunity to assist in a survey of the Greater Milwaukee Dental Association. The greater Milwaukee area is a major area in which people make use of the Medicaid Dental Program. This survey of members was quite eye opening. One of the questions in the survey asked if a member dentist participated in the Medicaid Program and if not, why not. Only 37% of respondents participated in the program. There were three major reasons dentists chose not to participate:

- **Poor Reimbursement**
- **Lack of patient commitment to both care and appointments**
- **Tremendous paperwork hassle.**

Since this survey I have had the chance to discuss this issue with area dentists. No less than eight have said they are seriously considering leaving the program. Typical of these stories is a true-life example I would like to relate; This dentist graduated in 1988 with a student loan debt of \$110,000.00. His monthly student loan payments alone are in excess of \$2000.00 a month and this will continue for 25 years from his graduation. These payments are solely his personal expenses not business expenses. He went into practice as an associate and had grandeur of helping all patients eliminate their dental problems. He was a Medicaid provider and thought he was doing a service for those less fortunate. His average no show rate for Medicaid patients was 60% compared to 6% for non-Medicaid. He was reimbursed at a rate of 35%, yet the expenses for his business ran 58% (please note this 58% does not even include any compensation for the dentist and is much better than the average). His attempts to reach the office of the Medicaid program administrators with problems or complaints would take days. Busy signals were the norm. Attempts to pre-authorize services often led to the patients being switched to the HMO version. After going to school for over 8 years to do everything possible to help patients obtain their optimal dental health, he found he could not do so because the system was broken. He dropped the program because he could no longer afford to participate. It is not that he does not believe in helping those less fortunate, last year he donated \$10,270.00 in services to those less fortunate and this year in addition to that he has joined the Donated Dental Services Program. In the five years since he has dropped out of the program nothing in this program has changed.

I offer you the following facts:

- **The average dentist goes to school for more than eight years.**
- **The average student graduates with debts between 80-90,000.00 and this is before they incur any debts to start their practice.**
- **Dentists who wish to become certified as Medicaid providers must complete a 32-page certification package, for a state that has licensed them.**
- **The average overhead for a dentist is 65-70% while Medicaid still routinely pays in the range of 35-50%. (Please note when you take into consideration the extremely high no show rate of Medicaid patients' overhead will rise).**
- **Dentists must now pay to be on the system via the use of the swipe card, which will raise expenses even more.**

- The Medicaid program still does not cover procedures it should and it requires pre-authorization for procedures, which do not usually require pre-authorization.
- In 1981, Wisconsin Medicaid paid \$25 million on dental claims. In 1998, Medicaid paid just under \$15 million on dental claims. This is a reduction of 40%! This year the budget calls for them to spend approximately \$12 million on dental claims so the budget increase will not even bring us back to last years expenditures.
- The Medicaid handbook is large and cumbersome due to the multitude of state and federal laws. The Department of Health and Family Services which is required by the state legislature to conform more closely to that of the private sector, cannot even conform to the handbook.
- The Wisconsin Medicaid program is a **\$2.5 BILLION** program and the dental component equals 7/10 of 1% of that.
- At the current time rate reimbursements for adults are based on 1991 fees and rate reimbursements for children are based on 1995 fees. These need to be brought up to date with fees for the most current year.

Our last two WDA Presidents have asked dentists to get more involved in the Medicaid Program. I agree 100%. We are the ones who have received the extensive training necessary to provide that care. However if the state wants dentists to participate in a governmental program they must give us a program that works and is fair.

Please don't misunderstand, I am not here to place blame, I am here to let you know this program needs to be changed and made fair. You are the only ones that can make that change. This is a system established, run, and mandated by the federal and state governments. The funny thing is no one has ever consulted with the people needed to make the system work, **THE DENTIST**. I strongly urge this committee to be at the forefront of helping create a better access to care. The starting point is approval of the rate increases for the Medicaid Dental Program. However the system needs a complete overhaul and only you can initiate that. I urge you to consider a committee (which should include input from dentists) to make sure this program becomes something which will start to work efficiently and be around a long time.

I would also like to take this chance mention my support for the capital budget proposal for the state assistance in building a new dental educational and clinical facility at Marquette University the states' only dental school. This is also important for access to care as our population is living longer and we face a shortage of dentists in the future and the influx of potential patients from Badgercare it is imperative that Marquette University Dental School remain a viable part of the state and the access to care issue.

One other piece of information that I think is important to include in the issues I have presented today. The dentist I mentioned earlier, is myself and I think it is a true shame that I no longer participate in this broken program.

Thank you for your time and hopefully my input has given you some ideas that you can use as you consider the Governor's budget proposal.

Joint Finance Committee Public Hearing - Tuesday, April 13, 1999

SB 45/AB 133
^

The proposed budget bill shows for an increase of 1.77% in the first year and 1% in the second year. This will not allow for the hiring of additional staff, increase of wages and the all important retention of employees. A 3.3% rate increase for Medicaid-certified nursing homes in each year would permit facilities to stay even with the forecasted 3.3% increase in health care costs due to inflation for 1999. Our facility Medicaid residents runs between 65 - 70% so an adequate Medicaid rate is crucial. Without an adequate Medicaid rate increase, the benefits of a wage pass-through will be lost. The 7% wage pass-through for all employees, except the administrator and home office staff would be eligible, and would be used to increase wages, benefits and the number of staff.

Fairchild Healthcare Center is the main employer in Fairchild, population of about 500 people, and it is vital that it stays functioning. With employment of 50 people, full-time and part-time, it provides the main source of income for some families and partial for others.

Our CNA starting wage is at \$6.75 with an average around \$7.75. With more and more new businesses starting up, some pushing the \$10.00 starting wage it is extremely important to stay competitive. Our facility is home to our residents and we want to continue the quality of care that we have been able to provide. Reading the help want ads in the Eau Claire Sunday paper, and seeing two solid pages of facilities looking for CNAs, RNs, LPNs and other staff, it is becoming a critical situation. The nursing home industry needs this 7% wage pass-through to continue to provide services to the elderly. I am sure most of you have someone you know that has been in a nursing home or is in one at this time. It is a very serious crisis and we need your help to assure that ample staff is available to provide the quality of care for your loved ones that the State of WI is so well

known for. Thank you for your support of the 7% wage pass-through for our nursing home employees and an adequate Medicaid rate increase.

-The MN Legislature last session passed nursing home wage pass-through legislation similar to what we are proposing. In a 3/10/98 editorial in support of that measure, the Minneapolis Star Tribune wrote:

"Every day, someone must feed, bathe and clothe many of the people who live in nursing homes. Someone must help many of them walk or get into a chair, or move their wheelchairs. Someone should greet them cheerfully, listen sympathetically, and offer the simple comforts of a smile and a tender hand.

Kenneth King, NHA

Kenneth King, NHA

Fairchild Healthcare Center

331 North St.

Fairchild, WI 54741

(915) 334-4311

Budget Proposal Outline

Presented by: Chris Witzany, pharmacist, Grantsburg Wi

4-14-99

DHSS BUDGET PROPOSAL TO REDUCE MEDICARE REIMBURSEMENT TO PHARMACY PROVIDERS BY 18% LESS THAN AVERAGE WHOLESALE COST

I. DHSS PROPOSAL IS BASED ON INCORRECT PREMISE THAT PHARMACIES CAN PURCHASE DRUGS AT 18% LESS THAN WHOLESALE COST.

A. No pharmacy in the U.S. let alone Wisconsin can purchase drugs at this cost

B. Pharmacies would dispense drugs at less than cost????

C. No business can survive selling at below cost

II. PHARMACIES IN NORTHERN WI SERVE A LARGE UNDERPRIVELAGED MEDICAID POPULATION

A. Create a hardship for elderly, disabled, and financially troubled people of community if local pharmacy could not serve them

B. Employee cuts in these pharmacies would lead to increase in unemployment.

C. Decrease in payroll affects other town businesses as well as decreased state income tax revenue

III. PHARMACY REIMBURSEMENT IS NOT CAUSE OF OUT OF CONTROL DRUG EXPENDITURES

A. Pharmacy reimbursement is currently LESS than 10 years ago but drug cost is still rising

B. 3 main reasons for large increase

1. Increase utilization --more people getting more prescriptions

2. Increase in current drug prices--some drugs increased 3000% in last year!!

3. Increase in new, very expensive medications

IV. ALTERNATIVES TO DECREASING PHARMACY REIMBURSEMENT

A. Electronic data management

B. Coordination of benefits with other insurance

C. Use pharmacists as a tool for formualry management & managment of expensive disease states i.e diabetes and asthma

**CUMBERLAND MEMORIAL
HOSPITAL PHARMACY
1110 7th Ave.
Cumberland, WI 54829**

**PROPOSED \$18 MILLION DOLLAR MEDICAID DOLLOR CUT
WITH GOVERNOR'S BUDGET**

1. Graph
 - a. Please note that the majority of a prescription cost is actual drug cost, not fee.
 - b. Note that the fee portion of the average prescription cost has remained relatively flat over the last 15 years approximately.
 - c. Appreciate that this graph is not inflation adjusted which would in fact put our fee portion in a decline over the last few years.

2. Local Effect at our Hospital
 - a. Estimated \$10,000 loss
 - b. ECU already is a breakeven operation
 - c. Would need to subsidize our nursing home with a mix of Fed and St. moneys from the hospital side of operations.
 - d. Hospital is 75% entitled already, with no extra money laying around for use. We essentially cost shift this state burden to that portion of the private pay/medical insurance sector of the market! This is unfair. Even you will feel the pain with reduced coverage and higher premiums!
 - e. We face having to evaluate our service and run the risk of selling off/giving away this prescription drug service to another larger provider to help that service stay solvent because we have too much overhead expense.
 1. Potential for a substantial reduction in care for our residents
 2. Potential for a substantial loss in continuity of care
 3. Loss of identity in a community

3. Ripple Effect (Trickle Down Economics)
 - a. If the Medicaid program institutes these types of fee reductions, every other carrier across the country will do precisely the same thing. The results will be devastating. I'm not so sure that our Wisconsin legislature wants to start such a negative National Trend!

4. Refusal of T-19 Recipients
 - a. Pharmacists are already talking about the real distinct possibility of refusing T-19 recipients similar to what the Dentists have done for years due to such poor reimbursement. The dentists either got or will receive a 10% hike in fees due to their poor reimbursement and refusal to see T-19 patients. Why can't we learn from them?

5. Why didn't the Governor enlist the State Associations help in developing more cost effective means to trim the budget than to slash the current fee structure? Our State Association has ideas ranging from raising the co-payment to reinstating the State adopted DUR program which saved millions of dollars by monitoring "proper drug utilization" from the T-19 claims submitted to the state for payment!

6. Drug Companies