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Joint Finance Committee Hearing

April 13, 1999

Amy Forst

On behalf of Marathon County Commission on Aging I wish to extend a welcome to the members of Joint Finance and express our appreciation to you for bringing this hearing to Central Wisconsin. My name is Amy Forst, I am the Senior Community Services Manager for Marathon County Commission on Aging. I am here on behalf of the Commission and Deb Menacher, our director, who had another commitment.

We urge you to consider the following budget priorities:

Family Care - We urge you to adequately fund all the pilot projects to serve all eligible persons over the next two years. If it is the desire of the legislature to fund pilots for other models that this be in addition to the funding already proposed for the currently identified pilots.

COP - Since Family Care is being piloted we must continue to eliminate or significantly reduce waiting lists in non-pilot counties. We should do this because Family Care is moving to provide choices and to eliminate waiting lists, and to continue the trend of reduced utilization of nursing homes. You made a good start on this with your increase in the budget adjustment bill to serve over 2,000 more people on waiting lists. It is estimated that the entire COP waiting list could be eliminated, not only for the elderly but also for people with disabilities for \$45 million GPR over the biennium. This amount would be matched by over \$65 million in federal matching funds under the COP waiver programs. While this is a significant investment, it actually represents only 13% of the tobacco settlement money.

Wages for Personal Care and Certified Nurses Aides - It has been well substantiated that wages and benefits are not adequate in either nursing homes or for personal care workers providing care in a person's home. This problem results in tremendous turnover and, therefore, a very negative impact on the quality of care. As we change the long term care system in Wisconsin we must assure that there are enough qualified workers to provide quality care in nursing homes and homes. It is imperative that a wage pass through to provide increases in wages and benefits for long term care workers be achieved in this budget.

Nutrition - Wisconsin's Elderly Nutrition program has proven to be the most cost effective way of helping older persons remain in their own homes. In the last 10 years the home delivered meal program has increased from 20% of the total program to 46% of the program. The average age of people who receive home-delivered meals is 81. At a cost of only \$1,500 per person per year it is probably the most cost-effective program that we have in Wisconsin. Participants pay almost 30% of the cost of home delivered meals through voluntary contributions. We urge increased funding for this vital program.

Transportation - We continue to struggle to meet the transportation needs of frail elders, especially in rural areas. An increase for Elderly and Disabled Transit programs could open the door to more accessible and affordable transportation for older adults. The Coalition of Wisconsin Aging Groups is supporting an increase of \$8 million a year. While this seems like a large increase, it is a small increase in real dollars (1% of the total DOT budget for the biennium).

I realize that we are requesting significant funding ⁱⁿ these programs. However, the 85+ age group is now our fastest growing age group. They are also the persons mostly likely to need supports in order to maintain independence in the community. If we as a State are serious about having community based care as a real option for frail elders, funding for these areas is essential and critical to achieving that dream.

Testimony
Joint Finance Committee
April 13, 1999

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I am speaking here today as the mother of a very wonderful young man who happens to be cognitively challenged. My son Travis is nearly 20 years old. He has received special education services through the schools since he was 3. Travis has always been a very social person. He loves to bowl and play softball on regular city recreational leagues. He also likes to earn his own money. Although he went through the high school graduation ceremony last spring, he has returned to school this past year in order to receive more job skills training, as this has not been available to him through the adult services system. He is currently working at a pet store, which he loves. When he began working there he needed one to one supervision. Once he began learning his job, the job coach backed off gradually, and he is now able to do his work independently. Unfortunately, this job is only available through the school as a training site for students. As of yet, the people in supported employment have not been able to find a job site for him. Apparently it is difficult to find employers who are willing to hire people with disabilities, even though funding for job coaching and training are presently available through the Division of Vocational Rehabilitation. (DVR). I have been optimistic, however, that it will be just a matter of time until the right match is found, and Travis is able to be productively employed. Unfortunately it is my understanding that the Governor's Budget proposal includes a decrease in funding for the services of Vocational Rehabilitation. Travis is capable of being a productive worker once he is placed in the right job, and given the intensive training available through the DVR funding. If funding is cut, the possibility of this happening will be seriously jeopardized for him. I may be politically naive, but it makes no sense to me that an administration which claims to be invested in putting people to work would cut funding for an agency designed to give people the support and training they need to be successfully employed.

The second concern I have for my son, and many other people with special needs, is that of housing options. Because Travis has impaired judgment, he needs fairly close supervision to ensure his safety. A few years ago we had hundreds of dollars of electronics equipment stolen from our home, as Travis let people he thought were friends into our home while I was at work. The older he gets the more difficult it has become to find routine, affordable supervision for him while I am away. In addition, while Travis is usually fairly good natured, he has on rare occasion, lost his temper while playing with neighborhood children. I am 47 years old and a single parent. It is already difficult to provide adequately for his supervision needs. Once he is out of school he will be unsupervised for most of the day, especially if he is not able to obtain suitable employment. The most logical solution would be for him to gradually transition into a supervised living arrangement of some kind. The group

homes, however, charge from \$1500 to \$3000 per month to cover room, board, and supervision. Travis receives about \$580 a month in federal and state social security payments. Even though I work both a full time and a part time job, it would be impossible for me to make up this difference.

In the 1970's deinstitutionalization occurred, and people who were moved out of institutions and into the community with the goal of providing more humane, cost effective care, were fully funded to be cared for in the community. Unfortunately those same dollars have not been provided to care for those people with disabilities who have been raised from birth by parents in their homes. There are now 2 generations of people who are waiting at home for services, with more generations to come. The state has not kept good on its promise to keep people out of institutions by providing adequate funding for community care. The majority of funding still goes to institutions to provide care for the small number of people with disabilities still residing there. The current budget proposal freezes funding for CIP programs which are already underfunded. What counties need to be able to provide suitable living arrangements for people are increases in fully funded CIP 1B slots. While Community Options is another very good program, I have been told that the waiting list for COP has not moved in 10 years in our county. It will take major increases in COP dollars to even begin to meet the need.

I am aware that Long Term Care Redesign has been proposed as a way of simplifying the funding system for the elderly and disabled, but this program has a long way to go before it will be fully implemented. It is my understanding that no dollar figures have been released, and it is just being piloted for people with disabilities in a few counties. Numerous questions remain regarding how and if it will be able to meet people's needs. I just sat in on a Senate Committee Hearing in which Secretary LeAnn told committee members that people would have a choice about services, as long as they choose the least expensive option. Either I missed something important, or client choice is nothing more than political rhetoric. Even if the program is successful, it will be years before it is fully implemented. People with disabilities and their families need help now.

The situation that My son and I, and many other families like us are faced with is this: We will have to get along as best we can until a crisis occurs. If Travis gets hurt or hurts someone else, or if I die, law enforcement and social services will be forced to intervene. It doesn't make sense for anyone to have to live on pins and needles waiting for a crisis to occur to obtain services. I ask you to continue to fund DVR services, and seriously look at those options such as fully funded CIP 1B slots to make supervised housing available for people with disabilities.

Thank you very much for your thoughtful consideration of these issues.



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 Governor's 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 let's 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



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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.'

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 get 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 RFDF 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

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 TV. He was tense, flinching with each sudden noise, as nurses 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, and 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, and thought 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 saying: "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 stained outside his door. Nor, his daughter lamented, did it 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.

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 RFDF'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.

Patiently 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, nondemanding 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

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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.

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.

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.

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



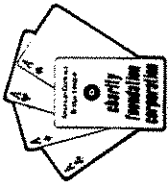
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Founded in 1980 by family caregivers, the Alzheimer's Association has more than 200 chapters nationwide providing programs and services, including support groups, to assist Alzheimer families in their communities. The Association is the leading funding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

Funding for this publication was generously provided by the American Contract Bridge League.

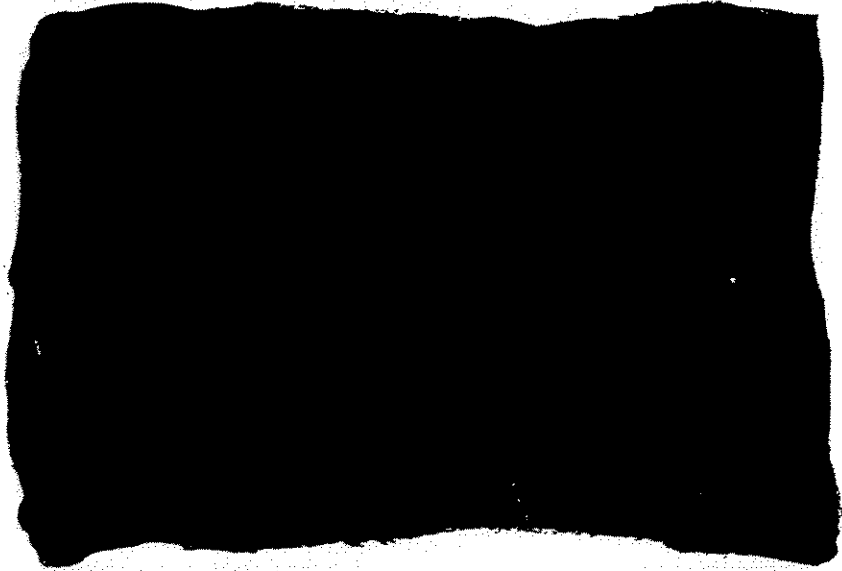


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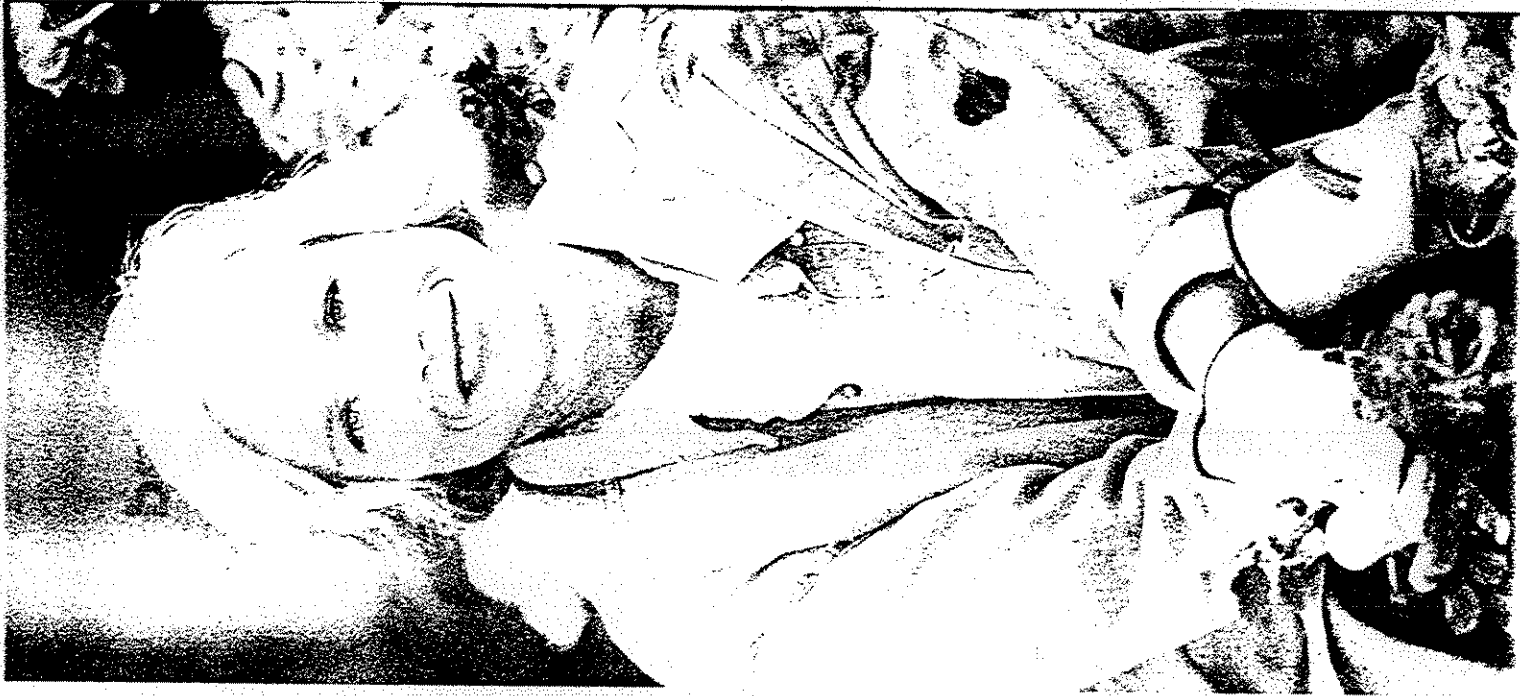
Someone to Stand by You

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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 of 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.



Diagnosing Alzheimer's

Probably the most incredible thing about Alzheimer's disease is that it is a progressive disease that slowly erodes a person's ability to perform the tasks of daily living. As a person's memory fades, they may forget names, faces, and places. They may also forget to eat, drink, or take care of themselves. In some cases, they may become so confused that they are unable to recognize their own family members. And, in some cases, they may become so agitated that they are unable to pay attention to anything else. It is important to seek medical attention if you notice any of these symptoms in yourself or a loved one. Early diagnosis and treatment can help to slow the progression of the disease and improve the quality of life.

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.



For more information, call 1-800-272-3900 or
the Alzheimer's Association chapter nearest you.
Or, you may contact us on the Internet at:
www.alz.org

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S IT ALZHEIMER'S?



WARNING SIGNS
YOU SHOULD
KNOW

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Someone to Stand By You

The Alzheimer's Association is the oldest and largest national voluntary organization dedicated to research for the causes, cure, and prevention of Alzheimer's disease and to providing education and support services to Alzheimer's patients, their families, and caregivers.

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.

Information on Alzheimer's disease, current research, patient care, and assistance for family caregivers is available from the Alzheimer's Association. For information, or the location of the chapter nearest you, call:

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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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SERIES



An Overview of
*Alzheimer's Disease
and Related Dementias*



ALZHEIMER'S
ASSOCIATION

Someone to Stand by You

What is Alzheimer's 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.

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 in family members were exposed to something in the environment that caused the disease.

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

Remembers later

Can follow written or spoken directions

Can use notes

Can care for self

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.

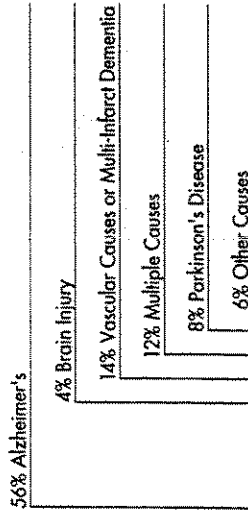
A Person with Alzheimer's Disease	A Person with Age-Associated Memory Problems
rarely	often
gradually unable	usually able
gradually unable	usually able
gradually unable	usually able

* Derived from the book *Care of Alzheimer's Patients: A Manual for Nursing Home Staff* by Lisa P. Gwyther, A.C.S.W.

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:

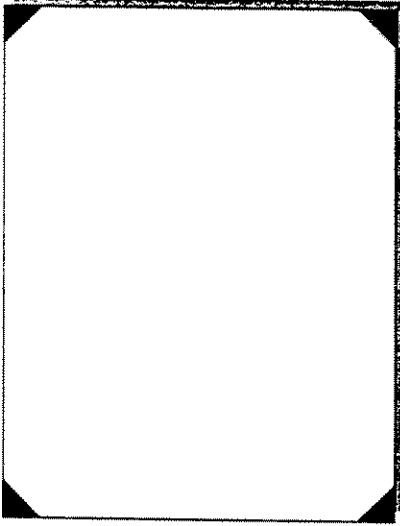
- ▶ *Is it Alzheimer's? Warning Signs You Should Know*
- ▶ *Steps to Getting a Diagnosis: Finding Out if It's Alzheimer's Disease*
- ▶ *Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease*
- ▶ *Steps to Understanding Challenging Behaviors: Responding to Persons with Alzheimer's 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) 335-8882
<http://www.alz.org>
email: info@alz.org

Contact the chapter nearest you.



ED205Z

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Joint Finance Testimony, April 13, 1999
Stevens Point, WI

Thank you for listening to WI citizens today. I am here representing Wisconsin's children. My name is Sue Weimerskirch and I am the Director of Prevention Services for Children's Service Society of WI., a State Wide Child Welfare Organization who's mission is to provide safe, nurturing homes for all WI children.

One of my roles, is that I am Director of the Start Right Program in Marathon County. In the year 2000, Start Right will offer home visitation services to all parents of newborns and will have established a network of 7 family resource centers throughout Marathon County to provide parents the education and support they need to raise healthy, happy children.

Start Right will have a year 2000 budget of about \$1'900,000, [REDACTED]. Funding is from a mix of local, state and federal dollars, including our newest funder, POCAN. I want other places throughout the state, to build comprehensive child abuse and neglect prevention programs like Start Right so that WI children can live without the consequences of child abuse and neglect.

I am here to advocate for the expansion of home visitation programs and Family Resource Center programs as proven strategies to prevent the high financial and human costs of child abuse and neglect. Seventy to eighty percent of children in juvenile correctional facilities have been abused or neglected. Children are our most valuable resource and we need to start acting like it! We know what works. Home visitation has proved to be the single most effective tool we have to prevent child abuse and neglect. I believe that we need to do the following:

We need to fund, with new money, the Truth In Sentencing promise of 1% or greater of the total Corrections budget going to child abuse and neglect programs. These new funds should be dedicated to preventing the first time occurrence of abuse or neglect.

Money should be allocated through local community teams, such as family preservation and support teams, to develop home visitation and family resource center programs that meet local needs. Community ownership breeds success and community investment of local financial resources to build programs.

Increasing the funding for POCAN is another way to expand home visitation programs. It makes sense to use TANF dollars to expand POCAN because those dollars, like POCAN dollars, are targeted to low income populations. In communities where child abuse and neglect programs exist, POCAN can provide the additional money through federal targeted case management dollars, that is needed to bring those programs to scale.

I know that it is difficult for each of you to listen all day long to the many needs that are brought before you. I urge you to listen to the voices for the children, as they cannot speak for themselves. Invest in child abuse and neglect programs. It will save the state many dollars in the future and children will not have to experience the pain that parental abuse brings them.

POCAN

General Information

The Wisconsin Child Abuse and Neglect Prevention Program (POCAN) under the authority of Wisconsin Act 293, creates funding for the provision of child abuse and neglect prevention services including home visitation to high risk, medical assistance eligible, first time parents; and provides a flexible fund to provide wrap around services to home visitation families and to families who have either been the subject of a child abuse or neglect report or who have asked for assistance to prevent abuse, who are willing to cooperate with an informal plan of services, and for whom there will be no court involvement.

POCAN is Wisconsin's policy initiative to provide funding for home visitation services on a broad scale, by utilizing the targeted case management benefit available to Medical Assistance eligible families.

A total of \$995,700 of state GPR is available for one year beginning January 1, 1999 - December 31, 1999, through the Division of Public Health. Projects are expected to bill for targeted case management to supplement their operations. Currently, nine counties and one tribe have received funding including: Brown, Door, Fond du Lac, Manitowoc, Marathon, Portage, Vernon, Waukesha, Waupaca and the Lac Courte Oreilles Tribe. There is support throughout the state to add 23 additional sites through the 1999-2001 state budget at a cost of \$2.1 million.

Children's Service Society's of Wisconsin's (CSSW) Position

CSSW's mission is to provide a safe, nurturing homes for Wisconsin children. Funding for home visitation services for at risk parents is an important component in preventing child abuse and neglect. CSSW advocates for increased funding to implement home visitation services throughout the state and supports POCAN as one strategy to make this happen.

- POCAN is a step in the right direction. With POCAN dollars, child abuse and neglect home visiting services can be provided to a vulnerable population. However, providing home visitation services to "at risk" populations is only a part of what we must develop in Wisconsin. To prevent child abuse and neglect, we must develop comprehensive, local family support programs that are available to all parents without regard to their socio-economic status or their eligibility for a federal program.
- In communities where comprehensive community based, community driven services to prevent child abuse and neglect exist, POCAN funding will infuse additional dollars into these programs allowing home visitation programs to expand.
- POCAN was developed by a joint Legislative Council Study Committee and has bipartisan support, and may be the best shot we have to increase funding for prevention of child abuse and neglect.
- Medicaid funding provides a substantial pot of funds for the partial reimbursement of home visitation services.
- POCAN presents an opportunity to take the home visiting model statewide. Home visitation of parents of newborns has nationally recognized credibility as a researched backed child abuse and neglect prevention strategy.
- POCAN provides funding for technical assistance and training to home visitation programs funded by POCAN at no cost. These training sessions will be available to all home visitation programs throughout the state at low cost. It is important that home visitation staff is well trained in a strength based philosophy and that programs are provided the information they need to maintain quality standards.

April 13, 1999

My name is Deb Knippel and I am a Prevention Specialist with Ministry Behavioral Health in Stevens Point. Much of my time is spent working with youth on alcohol, tobacco, and other drug abuse prevention. Tobacco is a gateway drug. That is, youth who begin using tobacco are at a higher risk for using alcohol, marijuana and other illicit drugs. Preventing the use of tobacco will reduce other risk behaviors.

Another part of my work involves teen tobacco-use cessation. As in other parts of our state, 37% of youth are smoking. If these youth continue smoking as adults, the smoking related costs to our state will be even greater than what they are today. There are very few cessation support services available for teens. Teens have very different needs than adults. We need additional research to find effective means to help teens quit smoking/chewing. I have co-facilitated smoking cessation programs in local high schools. Although the success rate has been low, participation is always high. We need more trained staff to reach more youth in more effective ways.

Wisconsin has a good start in tobacco use prevention but we need more. It is difficult to compete with the tobacco industry which spends 16 million dollars a day advertising a product that is the leading cause of death in our nation (8,000 Wisconsin citizens each year). We need more designated funding for tobacco-use prevention, research, and cessation.

I am asking you to financially support the measures outlined in the TRUST campaign:

1. 50 Million dollars dedicated annually to reducing tobacco use among youth and adults.
2. Funds designated for a comprehensive program which would use counter advertising, community-based initiatives and programs including enforcement of present laws relating to the sale of tobacco, cessation services for youth and adults, and evaluation and research for more effective services.
3. Funds be set aside in a way that they are committed to tobacco prevention and are not able to be influenced in any way by the tobacco industry or political action.

We will never receive this kind of money again from the tobacco industry. We must do all we can to protect this money and use it for the intent in which we went after it – to reduce the burden on our state related to the death and destruction of tobacco use.

Deb Knippel
1749 Elk Street
Stevens Point WI 54481



Tuesday, April 13, 1999

Ladies and Gentlemen of the Senate Health Committee and/or Joint Committee on Finance:

Tobacco kills nearly 8,000 people in Wisconsin each year. Our state's smoking rates exceed the national average with 36 percent of our young people smoking and 40 percent of pregnant women smoking. Caring for sick smokers cost over \$1.3 billion last year--that's \$267 for every man, woman and child in Wisconsin.

What lies before you this legislative session is a once-in-a-lifetime opportunity to lower the health and financial burden of tobacco. If you invest in a sustained, coordinated, comprehensive effort to reduce and prevent tobacco use in Wisconsin, **WE WILL SEE RESULTS!!!** Through similar programs, California, Massachusetts and even Florida after only one year, have all dramatically reduced their smoking rates. They have saved lives and dollars--but first they had to invest the money to be able to do it.

That's why over 80 health organizations and counting, from across the state, including the American Cancer Society, American Heart Association and the American Lung Association, have signed on to support a fair share of the money gained from Wisconsin's tobacco settlement to be used to reduce and prevent tobacco use. This Campaign is known as the TRUST Campaign (Tobacco Reduction Using the Settlement). Our Campaign is about three things:

1. **Tobacco Dollars for Tobacco Prevention:** Wisconsin should follow the National Centers for Disease Control guidelines and direct \$80 million, or half of the settlement dollars, into proven efforts that will help smokers who want to quit and prevent children and young people from ever starting to smoke or use tobacco.

2. This money will be used to **support a comprehensive program** that contains four essential components 1) Advertising to counter the use of tobacco, 2) Community-based programs and initiatives, 3) Services to help people quit using tobacco and 4) Evaluation and research to make sure the dollars are being used to support programs that are effective and science-based.

3. This **money be set aside and used to form a foundation, or a public/partnership** between the State's leading health organizations and the Legislature. This approach will ensure that the dollars are committed to tobacco prevention over time, isolated from interference from the tobacco industry, not subject to political censorship, and do not go to support or grow a governmental bureaucracy.

It may take great political will and courage on your part to see that these dollars are used to alleviate the tremendous problem that brought them here in the first place--the burden of tobacco. However, the long-term benefit will be real tax savings from reduced health care and other costs associated with tobacco use.

In the end, we hope you see these dollars as we do--as a golden opportunity and not a pot of gold.

Thank You,
Jennifer Peterson
2505 Pointe Road, Schofield, WI 54476
(715)359-1985

Statement Before the Joint Committee on Finance

**By
Sally Cutler
Assistant Director
Human Resources Development
Marshfield Clinic**

**13 April 1999
Stevens Point, Wisconsin**

My name is Sally Cutler. I am Assistant Director of Human Resources Development at Marshfield Clinic, Marshfield, WI.

I appreciate the opportunity to address the Joint Finance Committee today on issues relating to 1999 SB 45 and AB 133, the Governor's proposed 1999-2001 State Budget Bill. Thank you for coming out-state in order to hear central Wisconsin's points of view. The Marshfield Clinic system is well-represented on this panel, and we appreciate all they do on our behalf and on behalf of our patients and their constituents.

Marshfield Clinic is a Wisconsin not-for-profit corporation (an integrated system) engaged in the mission of providing quality health care, medical education and medical research in rural central, northern and western Wisconsin. Incorporated in 1916, Marshfield Clinic, including its 38 regional centers is held in a charitable trust. That is to say, Marshfield Clinic physicians do not build up equity within the Clinic as in other physician practices. We serve over 300,000 people. Many of our centers are located in medically underserved areas as well as health professional shortage areas (see Attachment 1).

We applaud the Governor for many of his efforts to limit tax burden of Wisconsinites. And we appreciate, too, his ongoing efforts to maximize public and private resources to enable people to receive health care close to home. We look forward to continuing to work with him and with you to assure a healthy workforce for Wisconsin.

For purposes of today's statement, I would like to draw your attention to items in the Governor's proposed budget we hope you would consider modifying.

Pesticide Database System (PDS)

The Governor has recommended \$35,000 to fund a study to determine the feasibility of establishing a pesticide data base. We appreciate his endorsement of this study, however, we feel that a database is feasible and should cover indoor and outdoor pesticide use. We feel also that the estimated \$400,000 cost of creating a pesticide use database would be consistent with other Gubernatorial recommendations as developing GIS and computer programs for environmental purposes.

Marshfield Clinic is part of a coalition of agricultural, public health, environmental and community organizations who have come together to urge the creation of the State's first comprehensive pesticide use database. As you may be aware, little data exists on pesticide use despite the fact that pesticides are used all around us at home on our lawns, on lawns of schools and parks, on golf courses and elsewhere. A database system would provide answers for researchers and the public on the impact pesticide use has on their health and environment. At Marshfield Clinic's National Farm Medicine Center, reference to a comprehensive database, including agriculture, residential and other non-agricultural uses, would assist researchers studying relationships between pesticide exposure and people with acute or chronic medical conditions.

Tobacco Settlement

The Governor has recommended investing around \$4 million in new initiatives on efforts related to tobacco of a possible \$338 million from the settlement payment to Wisconsin expected over the next two years. We are disappointed that the Governor did not consider a higher level of effort toward a preventable health risk. Marshfield Clinic has supported community-based tobacco prevention efforts in central and northern Wisconsin for many years. Marshfield Clinic physicians observe daily illnesses and conditions which are a result of tobacco use. As a result of knowing all too well about the consequences of tobacco use, Marshfield Clinic supports preventing and reducing tobacco use in Wisconsin through comprehensive programming funded by tobacco settlement dollars.

Healthy People 2010 Objectives: Draft for Public Comment. "Controlled-design community research studies and evidence from CA and MA have shown that comprehensive programs can be effective in reducing per capita tobacco consumption."

"Efforts to reduce tobacco use in the US have shifted from focusing primarily on smoking cessation for individuals to focusing more on population-based interventions that emphasize prevention of initiation and reduction of exposure to environmental tobacco smoke. Federal, state and local government agencies and numerous health organizations have joined together to develop and implement prevention activities based on this approach. This change from emphasis on individual behavior to emphasis on population-based strategies has come about because tobacco use appears to be susceptible to changes in the social environment."

"Based on research findings and the experience of State and Federal tobacco control programs, there are six key components of tobacco use prevention and control interventions: 1) prevention and restriction of minors' access to tobacco; 2) treatment of nicotine addiction; 3) reduction of exposure to secondhand smoke; 4) counteradvertising and promotion; 5) economic incentives; and 6) product regulation." Institute of Medicine. *Growing Up Tobacco Free: Preventing Nicotine Addiction in Children and Youths*, Washington, DC: National Academy Press, 1994

Senator Shibilski, we know you've been working on development of a compromise on this topic and we thank you very much for that. We know, too that other members of this committee support use of the Tobacco Settlement funding for these purposes beyond what the Governor has suggested.

Last week a bipartisan group of key legislators announced plans to push legislation setting aside \$50 million a year for tobacco prevention. The bill draft LRB 2413 would guarantee that Wisconsin implements an effective tobacco prevention program like those already working in other states e.g., Massachusetts and Florida.

We urge the Committee to seriously consider this compromise in your deliberations. The direct health care costs attributable to smoking exceed one billion dollars each year. Much of this cost is paid by Wisconsin taxpayers.

School to Work

Currently the State Budget provides funding for School-to-Work activities as well as school districts and local contributions (Marshfield Clinic pays approximately \$3,600 annually.) Marshfield Clinic is involved in many school-to-work activities throughout the system: Rice Lake, Park Falls, Minocqua and Ladysmith to name a few. At the Marshfield Center, Marshfield Clinic is actively involved in a consortium made up of 7 school districts, the technical college, 14 businesses and Marshfield Area Chamber of Commerce and Industry, MACCI. The group is facilitated by our Marshfield area local School-to-Work Coordinator and works on the following activities:

- meeting once per month for consortium and each apprentice advisory group.
- Coordinating placement of 148 students (Marshfield Clinic 11) in coop programs
- Coordinating placement of 42 students (Marshfield Clinic 3) in apprenticeship programs
- running mentor training programs 3 times a year for business
- marketing and communicating School-to-Work activities

The results of these activities have been excellent.

Marshfield Clinic is specifically involved with the School-to-Work in producing a Career Health Day, hiring Coop students, and providing leadership and placement in the Health Youth Apprentice program.

The Governor is proposing a nine-member board to over see the School-to-Work activities. We believe one-half of the membership should be from business and industry rather than one representative.

A decrease in funding from the State of Wisconsin for coordinators at the local level will be forcing businesses and schools to either:

- a. increases their local funding and contributions or
- b. decrease the activity.

Business and Schools cannot prioritize the funding or time for coordination that comes from a designated coordinator funded through School-to-Work dollars. When every school has their own coordinator the activity becomes disjointed, too time consuming for local business, and easy to ignore. Without coordinated effort, Marshfield Clinic Marshfield Center would have over 15 schools wanting different programs and access to experience.

The Marshfield consortium was planning to increase:

- Number of students involved
- Number of schools involved
- Frequency of mentor training
- Evaluation of current activities

Specifically several of Marshfield Clinic temporary, permanent and summer research students have come from the School-to-Work activities.

The overall reason for supporting the funding increase is because:

1. The entry workforce is declining in numbers. The opportunity for an experiential career opportunity of our youth is essential to
 - minimize dollars spent in post secondary institutions for students without a career focus
 - decrease the numbers of employees recruited who after employment find health care a bad career match
 - increase retention in the health care system and other businesses.
2. The increased funding for central coordination is important. This is better leveraged on a grant competitive basis for coordinators rather than directly to the technical colleges.

In summary, Marshfield Clinic recommends replacing the lost federal School to Work seed dollars with state GPR in order to fund grants to local Chambers of Commerce for local coordinator activities. Additionally we recommend funds allocated for School to Work be used for all students and not just TANF eligible students.

Area Health Education Centers (AHEC)

The mission of the WI AHEC System is to improve access to health care in WI's underserved communities through the development of community-based, culturally relevant, collaborative, health professions education programs. The WI AHEC System accomplishes this mission by fostering cooperation and collaboration among WI's health professionals, educational institutions and communities.

Federal core funding was used to initiate WI's AHEC System. Federal funding is designed to decrease over a nine-year period with the expectation that the state support would increase over time. The Joint Finance Committee increased state support to the AHEC system in 1997-99 State budget. The current state budget provides \$800,000 annually. Current federal funding level is \$763,434. Federal core funding expires in September 1999. WI can compete for State-Supported Model AHEC Program funds federally but if successful in that competition, the maximum funding would be \$60,000 annually per center. Marshfield Clinic supports an increase of at least \$700,000 in the State Budget annually for purposes of maintaining current programs and services.

Northern AHEC has been very helpful in providing coordination, communication and assessment as a neutral party throughout Northern WI. It has been through its efforts that Marshfield Clinic has been successful with the following projects:

- *Continuing Education Video Conference Series--Howard Young and Marshfield Clinic sponsored Pharmacy Continuing Education Series
- *Medical and Graduate Student Placement--Increased placement of Medical and Graduate students into the rural areas such as Minocqua
- *Cultural Awareness Education--Coordination and sponsorship with Marshfield Clinic in bringing Native American Culture through workshops to three northern communities
- *Health Education Efficiency --Building an infrastructure that brokers on-going educational activities throughout Northern Wisconsin that increases delivery and decreases duplication of effort
- *Facilitation of Planning--Northern AHEC has sponsored several strategic planning sessions that bring a variety of health organizations to the table to plan for needs in education

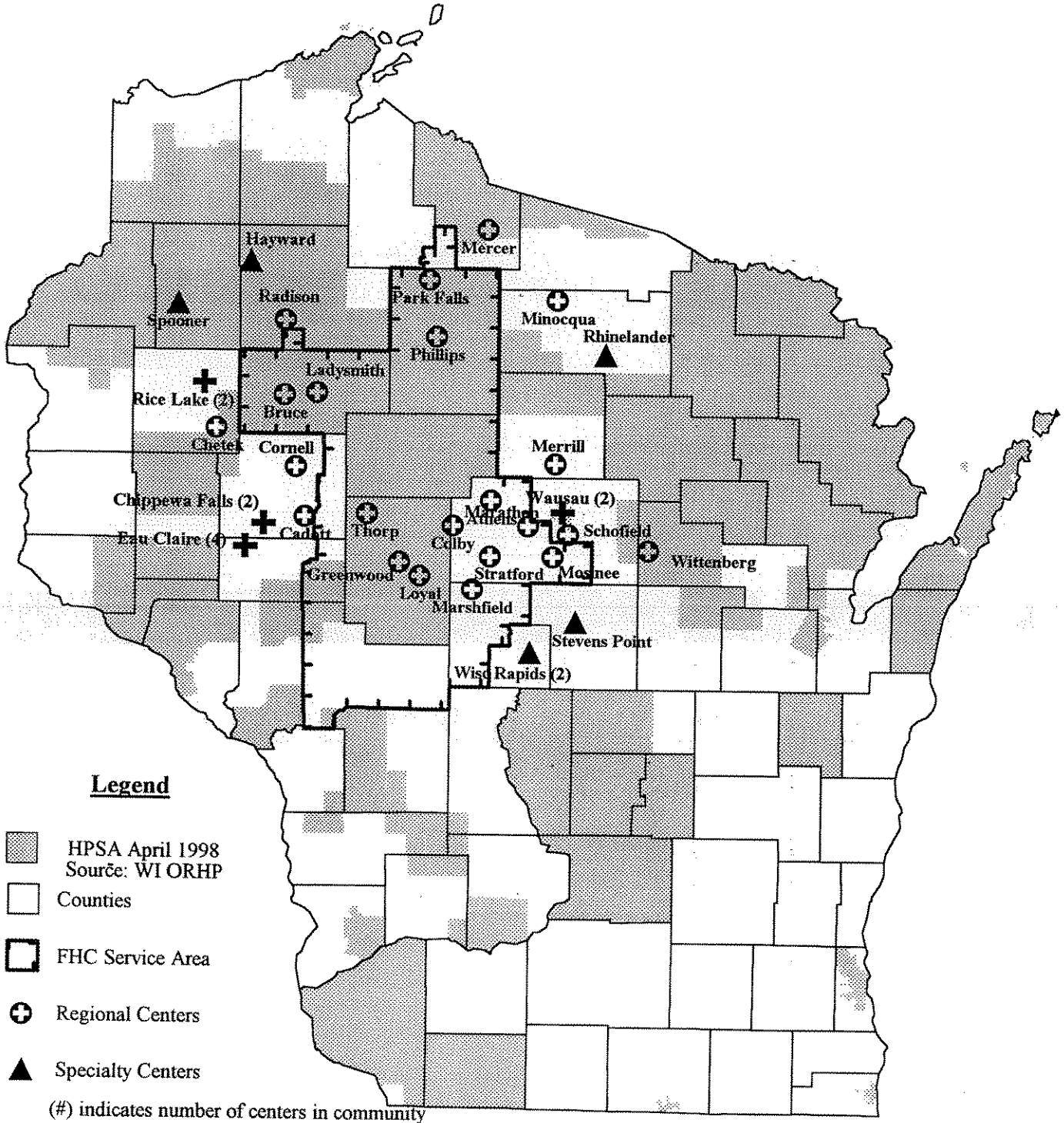
Specifically AHEC has been able to help Marshfield Clinic leverage and strengthen our effort in the communities by connecting us to other health organizations to work together. We have worked with Howard Young Medical, Lakeview Hospital, Lac du Flambeau, Lac Courte Oreilles, Wausau Hospital and Great Lakes Inter-Tribal Council to name a few.

In summary, AHEC provides more education with fewer dollars while at the same time listening to the communities and meeting their needs. We hope the Legislature would increase spending.

The concept that properly motivated medical schools can help to address state-level problems in physician distribution received additional support in a 1/20/99 *JAMA* article reporting on the direct and long-term impact of a special program to address the rural physician workforce of the Jefferson Medical College in Pennsylvania. The authors conclude that their program after 22 years "has had a disproportionately large impact on the rural physician workforce, and this effect has persisted over time. Based on these program results, policy makers and medical schools can have a substantial impact on the shortage of physicians in rural areas." As a rural institution, we are a consumer of the output of health professions schools. Given our dedication to bringing care as close as possible to the patient, we ought to continue to support educational interventions that help to address educational and health professions workforce deficits in underserved areas of the state.

Again, my thanks for the opportunity today to address Biennial Budget issues before you. Please don't hesitate to contact us for additional information on this or other items which come before your committee.

Health Professional Shortage Areas (HPSA), Family Health Center Service Area (FHC) and Marshfield Clinic Regional Center System



Marshfield Center for Health Services Research

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Testimony for Joint Finance Committee
Public Hearing 4-13-99

My name is Janet Zander. I am the Director of the Portage County Department on Aging, a board member of the Wisconsin Association of Aging Unit Directors, an advocate for older adults, and a member of a family with aging relatives. I want to thank the members of the Senate and the Assembly for their ongoing support of aging programs and request that this Committee take into consideration the following recommendations:

1. With nearly 11,000 people currently on the waiting list for COP funded services, increasingly narrowing definitions of services covered by Medical Assistance, vast geographical differences in service availability and waiting lists varying from days to years, long term care (LTC) funds not following individuals - if someone moves they may have to go to the bottom of a new waiting list, an obvious institutional bias -forcing some persons into more expensive and more intensive care prematurely, and dramatic growth in the older adult population on the horizon - **THE LONG-TERM CARE SYSTEM MUST BE REDESIGNED NOW**. We are looking at major changes in a very large system. This will not happen overnight. If we do not begin now, the current system will never be able to handle future needs. Funding to begin piloting all components of Family Care - Care Management Organizations (CMO) and Resource Centers (RC) must be made available in this next budget. The current situation of entitlement to nursing home care for low income individuals in need of skilled care and long waiting lists for those same individuals choosing community based services, just doesn't make sense. **All** persons in need of long term care should be able to access the LTC system for both case management and access to negotiated provider rates. It makes no sense to have individuals making decisions without full knowledge of their choices and without being able to benefit from cheaper service rates negotiated by CMO's. Inability to do these two things results in the spending down of assets more quickly and becoming dependent upon public subsidies to pay for needed care.

Family Care should:

- A) adequately fund pilot counties- capitated rates for individuals enrolled in CMO's, as well as the I & A, screening, and prevention functions of Resource Centers.
- B) be renamed to more appropriately describe who the program is designed to serve.
- C) not require pilot counties to undergo major structural changes during the pilot period (while the program is still being tested and refined).
- D) give pilot counties adequate time to truly test these new concepts. Once pilot counties begin receiving capitated rates they should be guaranteed 4 to 5 years without competition.

- E) restore the requirement that pilot counties must create local LTC Councils to assure local accountability and control.
2. With only nine counties participating in CMO demonstrations and Resource Center pilots it is imperative that funding for COP be increased in this next budget to address the 63 counties that are not yet participating in Family Care pilots. **A \$45 million increase over the next two years will create approximately 5,000 new COP slots.**

3. Rising costs; an increasing population of frail, older adults; and increased demand for home-delivered meals (HDM) makes it critical that state funding for the Elderly Nutrition Program be increased. There has been a 99.4% increase in the demand for HDM. Over 80% of HDM participants and over 50% of congregate participants are in the moderate to high nutritional risk category. A study conducted by the U.S. DHHS revealed that 80% to 90% of HDM recipients are low income. Despite this, participant donations account for 27% of the total cost of the program.

The HDM program is considered the corner stone of the LTC service delivery system. **Delivery of a daily meal provides a cost effective deterrent to premature nursing home placement for some individuals.** It also allows family members the ability to focus their energies on other needs an individual may have. **I ask you to support the Wisconsin Association of Nutrition Directors (WAND) request for an additional \$3.6 million.** Over the past 11 years, there has been only a 23 cent per meal increase in funding for Nutrition.

4. **I am requesting your support of the Wisconsin Personal Services Association proposal to increase the Medicaid rate for in-home Personal Care for the elderly and disabled by \$4.00/hour.** The \$ 11/hour increase in the year 2001 proposed in Governor Thompson's budget does not begin to address the critical shortage of workers home care agencies are currently facing. The ability of home care agencies to pay a living wage and offer valued benefits will aid their efforts to recruit and retain quality workers.

In the past several years, many home care agencies have been forced to close their doors. This current trend is contradictory to Wisconsin's goal of helping people who need care to remain in their own homes. It now costs the State \$782/month for the average Medical Assistance Personal Care client. If the State funds the \$4.00/hour increase the average per client amount would increase to \$906/month. If even 10% or 650 of the 6500 persons currently receiving personal care have to go into a nursing home due to the lack of available workers, the cost of providing care for these clients increases to nearly \$3,000/month for a total increased State cost of \$15.7 million. It makes good sense to provide the services people need to remain in their own homes. For individuals choosing to be cared for in their own home, over 80% of their care needs are met by family members and friends. These contributions of human resources are lost when an individual is forced to move from their home prematurely.

Four home health agencies in Portage County no longer offer MA Personal Care services because their costs exceeded the reimbursement rate. Long term care service providers at all ends of the spectrum must be able to recruit and retain quality workers to provide this very basic and essential care needed by some of our state's seniors.

5. Over the past several years, the total state and federal transportation budget has increased by astronomical proportions. Yet, increases for Elderly and Disabled Transportation programs have been minuscule with no increase at all in 1997 and 1999. A growing older adult population coupled with a trend toward development of regional speciality medical services have placed increasing demands on transportation programs. Transportation programs have been forced to place increasing restrictions on the amount of available transportation service for medical appointments, nutrition needs, and other critical needs. As the population of frail, older adults continues to increase we must be ready to offer those who have needed to give up the privilege of driving some reasonable access to needed services. **I am asking you to consider an \$8 million increase in each year of the next biennial budget.**

I appreciate your willingness to hear my testimony. We cannot afford further erosion of services that were developed to protect our state's vulnerable elderly. Tax cuts are not a priority at any expense. If cuts in state taxes means an increase in local property taxes, an erosion of critical services, increased out-of-pocket expenses to those that cannot afford to pay, a shortage of much needed front line workers, or forcing families to forego employment so that they can struggle to meet all of the needs of a chronically ill family member; then that is not in the best interest of either the health and well-being of individual citizens or our communities. It is time to re-prioritize the state budget to offer increased funding for programs that support our state's most valuable resource, human beings.

Thank you.

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

SB 45/AB 133
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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

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Portage County Retired & Senior Volunteer Program

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April 13, 1999

Comments to Joint Finance Committee regarding budget increase for Wisconsin's 17 RSVP projects:

My name is Marti Sowka and I am the director of the Portage County Retired and Senior Volunteer Program and president of the Wisconsin Association of RSVP Directors. As you know, RSVP is a volunteer program in which people age 55 and over find meaningful involvement in the community through volunteer service, utilizing the skills and experiences developed over a lifetime to address critical community needs.

I want to thank the members of the senate and assembly for their ongoing support of RSVP and request that this committee consider an increase in state funding of \$587,500 per year to expand the impact of RSVP.

RSVP is getting things done in Wisconsin because the state invests in a valuable human resource like seniors in service. Let me tell you a brief story of how increased funding benefited Portage County RSVP. With some new federal money two years ago we were able to begin a volunteer grandparent visitor program at the local juvenile detention facility. In 1998 14 volunteers visited 481 juveniles in a small group setting. 73 juveniles requested and received a one-on-one visit from a volunteer to set goals for release so the juvenile can work to avoid the behavior that landed him or her in detention. After several months of work, the volunteers came to RSVP staff and asked if there wasn't some way to reach these kids before they end up in detention. We worked with a local junior high school that was starting a program for at risk kids with poor academic performance and low attendance and provided classroom mentors whose role is to nourish a love of learning by sharing experiences and giving gentle positive encouragement. And it is working. The school reports that attendance improved by 50% and grades by 13% for students in the program. The school is now exploring charter school status and invited one of the RSVP volunteers to sit on the planning committee. This program continues to grow because the volunteers are making a difference and also positively addressing stereotypes held by young and old about each other.

That is one story about one program in one community. Multiply that and you begin to see the impact senior volunteers have on their communities. I will leave you with copies of a local fact sheet as well as a state wide fact sheet that includes impact statements from each project as well as a specific funding request.

Thank you.

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