

# ALZHEIMER'S DISEASE IN A CHANG- ING HEALTH CARE SYSTEM: FALL- ING THROUGH THE CRACKS

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HEARING  
BEFORE THE  
SPECIAL COMMITTEE ON AGING  
UNITED STATES SENATE  
ONE HUNDRED FOURTH CONGRESS

SECOND SESSION

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WASHINGTON, DC

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APRIL 23, 1996

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**Serial No. 104-12**

Printed for the use of the Special Committee on Aging



U.S. GOVERNMENT PRINTING OFFICE

24-799 CC

WASHINGTON : 1996

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For sale by the U.S. Government Printing Office  
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402

ISBN 0-16-052943-3

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# HEARING ON ALZHEIMER'S DISEASE IN A CHANGING HEALTH CARE SYSTEM: FALL- ING THROUGH THE CRACKS

TUESDAY, APRIL 23, 1996

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.*

The committee met, pursuant to notice, at 10:02 a.m. in room 106, Senate Dirksen Building, Hon. William S. Cohen (chairman of the committee) presiding.

Present: Senators Cohen, Grassley, Craig, Burns, Pryor, Feingold, and Warner.

Staff present: Mary Berry Gerwin, Priscilla Hobson Hanley, Victoria Blatter, Sally Ehrenfried, Elizabeth Watson, Lindsey Ledwin, Theresa Forster, Theresa Sachs, Sumner Slichter, Brooke Roberts, Patricia Deutsche, Rimmel Dickinson, and Ted Totman.

## OPENING STATEMENT OF SENATOR WILLIAM S. COHEN, CHAIRMAN

The CHAIRMAN. Today the Senate Special Committee on Aging is holding a hearing on the effects of the changing health care system on individuals who are touched by Alzheimer's Disease.

Over 4 million Americans now suffer from Alzheimer's disease, the cruel, degenerative brain disorder that robs its victims of their ability to control thoughts, memories, and language.

The Alzheimer's epidemic is spreading rapidly as our population ages. By the age of 85, one out of every two Americans will get this devastating disease.

Estimates are that in just about 50 years from now 14 million Americans—that's more than the current total population of Texas—will be diagnosed with Alzheimer's Disease. These numbers make Alzheimer's one of the greatest health threats facing our rapidly aging population.

The statistics are even more sobering when we consider that the casualty count of Alzheimer's extends well beyond those actually diagnosed with the disease, itself. We need only look into the face of a wife whose husband no longer recognizes her, feel the worry of sons and daughters struggling to find care for their parent who can no longer live alone, or hear the sighs of exhausted family members who provide round-the-clock devotion to realize that the reach of the Alzheimer's beast stretches far beyond its immediate prey.

This is not a disease of the aged, alone. Increasingly, this crushing diagnosis is being delivered to persons in their 40's and 50's, striking them down at the very time they're still struggling to raise their own families.

Last year the committee heard poignant testimony from Frances Powers of Lebanon, PA, a courageous mother of two who was diagnosed with Early Onset Alzheimer's at the age of 45. Mrs. Powers shared with us a brief glimpse of what it was like to live with an Alzheimer's diagnosis.

She told us "I know a lot about what I am walking into because I took care of my mother (who also had Alzheimer's) and I watched her vanish as a person. My children are now watching me. When I told them I had Alzheimer's disease, each cried and said, "You won't know who I am!" My children experience constant grief. If I had cancer I would probably die within a few years with my mind intact, but with Alzheimer's they will watch me drift away day by day. They will also watch a personality change that will be filled with frustration, anger, and rage."

As we all know, our health care system is facing dramatic changes as both government and private sectors move to contain skyrocketing health care costs. The need to control these costs is indisputable.

To give you an example, Medicare is on the road to the poorhouse. Without change, Medicare becomes insolvent next year and will go bankrupt just 6 years from now.

Medicaid costs are breaking the budgets of State governments. Between 1984 and 1994, combined Federal and State spending on Medicaid nearly quadrupled, and if no action is taken to control growth, Medicaid costs are going to double again by the year 2002.

Other private and public health care programs are trying desperately to contain runaway health care costs which far exceed the general rate of inflation.

The fiscal dilemmas now faced by government and private health care payers is only worsened by the huge wave of baby boomers poised to hit the shores over the next decades.

Today we are going to examine how changes in the health care system that are driven by these cost and demographic concerns may affect the millions of persons and their families who are afflicted with Alzheimer's disease.

The current health care system does not treat Alzheimer's families kindly. If you can look at this chart over to your left, you can see the complexity with which a family must navigate through this rather confusing web of programs and rules in order to receive care.

Tragically, this maze of bureaucracy faces the family at the very same time they're coping with the dreaded news of a diagnosis of Alzheimer's.

The current health care system provides little comfort and few answers to Alzheimer's families. There are no known cures, and doctors and other health care providers often do not coordinate their care. Hospital and acute care is provided by Medicare or private insurance, but the long-term care needs of families are often borne by Medicaid. And as families dealing with the disease can attest, there is little coordination between these two programs.

The Alzheimer's patient's care is squeezed to fit within the boxes of bureaucracy, and in the process there is no one place that takes into account the overall needs of the person or the family, as a whole.

This segregation of care has human and financial consequences, particularly as Medicare and Medicaid are undergoing changes to cut costs.

Increasingly, Alzheimer's patients may be tossed back and forth between these programs in efforts to shift costs from one to the other, and in doing so, the programs fail to recognize that coordinating the care of the patient can often be very cost-effective, such as by avoiding costly hospitalization through better preventive care.

So today we are going to examine how trends toward managed care in both government and private health care programs will affect the quality and the availability of care for Alzheimer's patients. The spread of managed care provides, I think, tremendous potential for better coordination of the care of patients with chronic conditions, thus improving the system for Alzheimer's patients and their families.

By the same token, we have to be careful. We've got to ensure that in the zeal to cut costs, managed care plans do not unduly restrict patients' access to necessary and appropriate care.

Today we're going to hear testimony from experts on the potential that managed care holds for coordinating care, both in terms of quality of care and in cost savings to the system, and the pitfalls that we have to avoid to ensure that care is not worsened through efforts to manage costs, while not truly managing quality care.

Today's hearing is going to examine how the current system is overly-fragmented, as that chart again will demonstrate, and fails to adequately provide non-medical social services that are so vital to persons with Alzheimer's disease. Since about 7 of every 10 persons with Alzheimer's still live at home, how we help families meet this care-giving burden is a crucial issue we must face as we consider changes in Medicaid and other programs providing care.

We are pleased to have with us family members who are going to provide us with their personal perspectives on the daily challenges they face in caring for their loved ones with Alzheimer's and the battles they have to wage day after day in trying to obtain care.

We're also going to hear from several experts who will provide us with their views on what is broken in the current system and how better coordinating and integrating services for Alzheimer's patients can improve the quality of care and can also be cost-effective for the health care system as a whole.

There are steps we can take to better integrate care. Last year, for example, the Balanced Budget Act that was passed by Congress but later vetoed by President Clinton included a demonstration project to allow 10 States to pool their Medicare/Medicaid dollars to create a more balanced and cost-effective acute and long-term care delivery system. This program would help States develop better ways to manage the treatment of persons with chronic conditions and offer elderly and disabled Americans more coordinated care, including case management and preventative care.

These are the kinds of steps that we need to take to eliminate the bureaucratic barriers that discourage coordinated care.

I'm looking forward to hearing the testimony of our witnesses today. I want to thank each of them on this panel and the subsequent panel as we examine how we can improve the care for Alzheimer's patients and the millions of Americans with chronic health care conditions.

[The prepared statement of Senator Cohen follows:]

PREPARED STATEMENT OF SENATOR WILLIAM S. COHEN

Today the Senate Special Committee on Aging is holding a hearing on the effects of the changing health care system on individuals touched by Alzheimer's disease.

Over 4 million Americans now suffer from Alzheimer's disease, the cruel, degenerative brain disorder that robs its victims of their ability to control thoughts, memories, and language. The Alzheimer's epidemic is spreading rapidly as our population ages. By age 85, one out of every two Americans will get this devastating illness.

Estimates are that in just about 50 years from now, 14 million Americans—that's more than the current total population of Texas—will be diagnosed with Alzheimer's disease.

These numbers add up to make Alzheimer's disease one of the greatest health care threats facing our rapidly aging population.

The statistics are even more sobering when we consider that the casualty count of Alzheimer's extends well beyond those actually diagnosed with the disease.

We need only look into the face of a wife whose husband no longer recognizes her, feel the worry of sons and daughters struggling to find care for their parent who can no longer live alone, or hear the sighs of exhausted family members who provide round-the-clock devotion, to realize that the reach of the Alzheimer's beast stretches far beyond its immediate prey.

This is not a disease of the aged alone. Increasingly, this crushing diagnosis is being delivered to persons in their 40's and 50's, striking them at the time that they are struggling to raise their own families.

Last year, the committee heard poignant testimony from Frances Powers of Lebanon, PA, a courageous mother of two, who was diagnosed with Early Onset Alzheimer's at age 45. Mrs. Powers shared with us a brief glimpse of what it is like to live with an Alzheimer's diagnosis. She told us:

"I know a lot about what I am walking into because I took care of my mother (who also had Alzheimer's) and watched her vanish as a person. My children are now watching me. When I told them I had Alzheimer's disease, each cried and said, 'You won't know who I am!' My children experience constant grief. If I had cancer I would probably die within a few years with my mind intact but with Alzheimer's they will watch me drift away day by day. They will also watch a personality change that will be filled with frustration, anger and rage."

As we all know, our health care system is facing dramatic changes as both the government and private sector move to contain skyrocketing health care costs. The need to control costs is indisputable. For example:

- Medicare is on the road to the poorhouse. Without change, Medicare becomes insolvent next year and will go bankrupt just 6 years from now.
- Medicaid costs are breaking the budgets of State governments. Between 1984 and 1994, combined Federal and State spending on Medicaid nearly quadrupled, and if no action is taken to control growth, Medicaid costs will double again by the year 2002.
- Other private and public health care programs are trying desperately to contain runaway health care cost acceleration, which far exceeds the general rate of inflation.
- The fiscal dilemmas now faced by government and private health care payers is only worsened by the huge wave of Baby Boomers poised to hit the shore over the next decades.

Today we will examine how changes in the health care system that are driven by these cost and demographic concerns may affect the millions of persons and their families who are visited by Alzheimer's disease.

The current health care system does not treat Alzheimer's families kindly. As this chart illustrates, the Alzheimer's disease patient and his or her family must navigate a confusing web of programs and rules in order to receive care. Tragically, this

maze of bureaucracy faces the family at the very same time they are coping with the dreaded news of a diagnosis of Alzheimer's.

The current health care system provides little comfort and few answers for Alzheimer's families. There is no known cure and doctors and other health care providers often do not coordinate their care. Hospital and acute care is provided by Medicare or private insurance, but the long-term care needs of families are often borne by Medicaid. As families dealing with this disease can attest, there is little coordination between these two programs. The Alzheimer's patient's care is squeezed to fit within the boxes of bureaucracy, and in the process, there is no one place that takes into account the overall needs of the person or family as a whole.

This segregation of care has human and financial consequences, particularly as Medicare and Medicaid are undergoing changes to cut costs. Increasingly, Alzheimer's patients may be tossed back and forth between these programs in efforts to shift costs from one to the other. In doing so, the programs fail to recognize that coordinating the care of the patient can often be very cost-effective, such as by avoiding costly hospitalization through better preventive care.

Today we will examine how trends toward managed care, in both government and private health care programs, will affect the quality and availability of care for Alzheimer's patients. The spread of managed care provides tremendous potential for better coordinating the care of patients with chronic conditions, thus improving the system for Alzheimer's patients and their families.

By the same token, however, we must ensure that in the zeal to cut costs, managed care plans do not unduly restrict patients' access to necessary and appropriate care. Today we will hear testimony from experts on the potential that managed care holds for coordinating care, both in terms of quality of care and cost savings for the system as a whole, and the pitfalls that we must avoid to ensure that care is not worsened through efforts to manage costs, while not truly managing quality care.

Today's hearing will also examine how the current system is overly fragmented and fails to adequately provide non-medical, social services that are so vital to persons with Alzheimer's disease. Since about 7 of every 10 persons with Alzheimer's still live at home, how we help families meet this care giving burden is a crucial issue we must face as we consider changes in Medicaid and other programs providing care.

We are pleased to have with us family members who will provide us with their personal perspective on the daily challenges they face in caring for their loved ones with Alzheimer's and the battles they must wage in trying to obtain care. We will also hear from several experts who will provide us with their views on what is broken in the current system, and how better coordinating and integrating services for Alzheimer's patients can improve the quality of care, and can also be cost-effective for the health care system as a whole.

There are steps we can take to better integrate care. Last year the Balanced Budget Act passed by the Congress, but vetoed by the President, included a demonstration project to allow 10 States to pool their Medicare and Medicaid dollars to create a more balanced and cost-efficient acute and long-term care delivery system. This program, based on long-term care legislation I introduced last Congress, would help States develop better ways to manage the treatment of persons with chronic conditions, and offer elderly and disabled Americans more coordinated care, including case management and preventive care. These are the kinds of steps we must take to eliminate the bureaucratic barriers that discourage coordinated care.

I look forward to hearing the testimony of our witnesses today and thank them for assisting the committee as we examine how we can improve care for Alzheimer's disease patients and the millions of Americans with chronic health care conditions.

The CHAIRMAN. With that, we'll hear from Senator Burns.

#### STATEMENT OF SENATOR CONRAD BURNS

Senator BURNS. Thank you very much, Mr. Chairman. Thank you for holding these hearings.

I don't think there is one of us in this room that hasn't been touched by this terrible condition. I know we have, and I have, and as our population lives longer and longer there will be hardly anybody that will not experience this terrible disease.

Though we've known about Alzheimer's a long time, it takes hearings like this to bring it to the forefront again and to remind people of the problems that we face with this terrible disease.



The facts of the impact of Alzheimer's disease are incredible. Over 4 million Americans have it, and its costs are astronomical, and the biggest share of those costs are borne by the families. The cost to the families works out to around \$18,000 a year.

I realize that we talk in averages. That is not always the case. If averages really work, if we had one foot in the oven and one foot in an ice bucket, on the average we should feel pretty good, but that's not the way it works. We know different circumstances prevail in the home, and the cost of nursing home care is much, much more than that.

I know we'll be looking at what effect managed care might have in taking care of the folks with Alzheimer's, but I think it's important to note that we'll be voting on legislation this afternoon that will have an impact, as well. Included in the Health Insurance Reform Act is a provision allowing taxpayers to deduct the cost of long-term health care insurance and expenses. This will be especially helpful to families of chronically sick loved ones, like Alzheimer's patients. I was proud to support that amendment because of the much needed relief that it provides, but there is more yet to be done.

I'd be interested to hear how managed care can help meet the needs of the people with Alzheimer's.

In a very rural State like Montana—and we have to remind ourselves how big we are, 148,000 square miles with only 850,000 people. Mr. Ryan understands that, as he has now made his home in Idaho—and how important distances and spaces become to us, does managed care or HMO's—will they really fill the void that is left sometimes? And in our particular case, maybe in States that are rural maybe they won't be able to do that as well as we would hope.

But as we continue to look at ways to improve Medicare and Medicaid, I think we need to pay special attention to long-term care, since that's the largest expense currently in the Medicare program. We certainly don't want to have anyone fall through the cracks.

I look forward to hearing from the witnesses today.

Mr. Chairman, I ask that my statement be made a part of the record and we hear from the witnesses, because the worst death in the world is to be talked to death by a bunch of politicians, so we come to listen. [Laughter.]

Senator BURNS. Thank you very much.

The CHAIRMAN. I'm not sure I'll include your full statement if it contains remarks like that. [Laughter.]

[The prepared statement of Senator Burns follows:]

#### PREPARED STATEMENT OF SENATOR CONRAD BURNS

Mr. Chairman, I thank you for holding this hearing. As I've mentioned in past hearings, my family has been touched by Alzheimer's—my wife's father suffered with it, and we suffered along with him, before he died about 3 years ago. As we live longer and longer, I think it will be rare to meet anyone who has not known a loved one with Alzheimer's. Though we've known about Alzheimer's disease for years now, it still takes hearings like this to bring to the forefront problems in coverage, challenges for the families, and barriers we must still tear down.

The facts of the impact of Alzheimer's disease are incredible. Over 4 million Americans have Alzheimer's and it costs our Nation over \$90 million each year. The great majority of that cost is paid by the families. It works out to about \$18,000 a year

to take care of a person with Alzheimer's at home, and that's with the families providing most of the care. The cost of nursing home care is two to three times that.

I know we'll be looking today at the effect managed care might have on taking care of folks with Alzheimer's, but I think it's important to note that we will be voting on legislation this afternoon that will have an impact as well. Included in the Health Insurance Reform Act is a provision allowing taxpayers to deduct the cost of long-term care insurance and expenses. This will be especially helpful for families of chronically sick loved ones—like Alzheimer's patients. I was proud to support that amendment because of the much needed relief it will provide, but there is more to be done.

I'll be interested to hear about how managed care can help meet the needs of people with Alzheimer's. In a very rural State, like Montana, where there is often only one health care provider in town, I imagine that would be considered managed care. As a general practitioner, he or she is charged with preventive care as well as treatment, and often see the patient through to the end of their ailment. If the patient should need more specialized care and is transported to a larger community, the general practitioner may lose his or her control over the care of the patient. But when the proper services are not available, the options are limited, and I'm not too sure that managed care or HMO's can help with that. In fact, Montana is still behind the curve on HMO establishment, and I think our long distances are just one reason.

But as we continue to look at ways to improve Medicare and Medicaid, I think we will need to pay special attention to long-term care, since that is the largest expense currently in the Medicare program. We certainly don't want to have anyone fall through the cracks and so I look forward to hearing from our witnesses today, not only to hear their personal experiences, but to hear what solutions they would propose. The best ideas often come from those in the trenches and some of our panelists today have been in the trenches for quite a while.

Mr. Chairman, though I have several hearings I'll need to attend this morning, I feel this is important not just to America's seniors but to all America. I will be following the proceedings closely and look forward to working with you to address this need. Thank you.

The CHAIRMAN. Senator Craig.

#### STATEMENT OF SENATOR LARRY CRAIG

Senator CRAIG. Mr. Chairman, my colleague from Montana has just set the stage, but let me, too, join in expressing my appreciation for you putting this hearing together today on Alzheimer's disease.

I am quite typical of a lot of people in the country today. I am the adult child of aging parents, and while this disease is not exclusively for the elderly, it certainly is one that preys upon them in ever-increasing numbers. I happen to be fortunate. My parents are healthy today. That is important to remember—tomorrow and the next day could be different. The costs that you have talked about in your opening comments, and that Senator Burns has talked about, and how we deal with this, how we coordinate the resources that are available in a more effective way are all important questions. I hope that this hearing can approach these issues as you've mentioned.

Senator Burns has also spoken about the effort that we are undertaking to reform health insurance to allow greater flexibility in the system. That is certainly an important bill that I hope can assist with these issues and this disease.

It is also my pleasure, Mr. Chairman, to have a fellow Idahoan at a hearing here in Washington, DC. I would just like to take a moment, Mr. Chairman, to thank Tim Ryan from Ketchum for coming here today to share with the committee some of his thoughts, his concerns, and the personal experience that he is going through with this devastating disease.

With that, Mr. Chairman, let me ask unanimous consent that my whole statement be part of the record.

The CHAIRMAN. Your full statement will be included in the record.

Senator CRAIG. Thank you.

[The prepared statement of Senator Craig follows:]

PREPARED STATEMENT OF SENATOR LARRY CRAIG

Mr. Chairman, I want to thank you for putting together today's hearing on Alzheimer's disease, and the problems that may be occurring, because of the changing dynamics of our health care system. As you know, Alzheimer's is a devastating disease affecting not only the life of the patient, but those around him or her as well. The drain on family members is both emotional and financial.

As an adult child with aging parents, I feel quite fortunate not to have had to face Alzheimer's disease personally. However, the experiences of other family members, friends and many of my constituents is very real. Therefore, I appreciate this committee's efforts to take a closer look at Alzheimer's, and how our health care system is, and isn't addressing the needs of patients and their families.

I hope that we can gain a better understanding of problems occurring today, and some idea as to how they may be addressed.

It is always a pleasure to have a fellow Idahoan at a hearing here in Washington, DC. I would just like to take a moment, Mr. Chairman, to thank Tim Ryan, from Ketchum, ID, for coming here today to share with this committee some of his thoughts, concerns and personal experience with this devastating disease.

Often we look at the problems associated with care of the individual stricken with Alzheimer's. In preparing for today, and looking over some of the written testimony on the problems with diagnosis, I was struck by our difficulty in dealing with this disease. I do, however, have faith in our health care system. And, with some changes to the system, we can certainly address this issue in a way that will help future generations. I hope we can also act swiftly to help those who suffer today.

I would just note the recent passage of a Dole/Roth Amendment to S. 1028, the Health Insurance Reform Act, which should provide some financial relief. The bill, as amended, would allow the following:

Penalty-free IRA withdrawals for large medical expenses;

Tax clarification of accelerated death benefits so that individuals may receive tax-free life insurance proceeds to help with the cost of chronic or terminal illnesses;

Tax deductibility of long-term care insurance and expenses, so that more Americans can protect themselves against financial difficulty in the event of a family member's serious chronic illness.

While these changes won't resolve all the problems we will be probing today, they are a step in the right direction.

In addition, passing a medical savings account program will provide yet another way for families and individuals to accrue savings that will assist in financing the costs associated with Alzheimer's.

Mr. Chairman, Alzheimer's disease depletes human resources, causes physical and emotional hardship for care-givers, and is a tremendous financial burden on families. Given the devastating nature of this disease, it deserves ample attention from the Congress. I look forward to hearing from today's witnesses on their thoughts about the ways that we, as a Nation, can better address this problem in a way that will meet the needs of those who are afflicted, and their families.

The CHAIRMAN. I'll call upon the Vice Chair of the Aging Committee. I should admonish you that Senator Burns has indicated that all of us should shorten our statements and simply listen to the witnesses.

STATEMENT OF SENATOR DAVID PRYOR

Senator PRYOR. I will take Senator Burns' admonition seriously, as I always do. In fact, I will just put my statement in the record, Mr. Chairman, and say thanks to our distinguished panel and all of those who are going to share their experiences with us. I think

almost every American family, in one way or another, is touched by this disease.

I want to thank you, Mr. Chairman, and I will just ask that my statement be placed in the record and express my deep gratitude. We'll have some questions later.

Thank you, sir.

The CHAIRMAN. Thank you very much, Senator Pryor.

[The prepared statement of Senator Pryor follows.]

#### PREPARED STATEMENT OF SENATOR DAVID PRYOR

Mr. Chairman, thank you for calling us together today to hear testimony on this important topic. I would also like to extend a special welcome to members of the Alzheimer's Association who are with us today. Thank you for taking the time out of your busy schedules to be with us.

Today we will be discussing an issue which is of great concern to me—how Alzheimer's disease patients will be affected by managed care. We all agree, for better or for worse, that managed care is the wave of the future. However, for the 4 million Americans afflicted with Alzheimer's disease, many questions have yet to be answered. Alzheimer's patients have special diagnosis and treatment needs. Will managed care organizations be able to respond to these needs? Or will individuals with chronic diseases like Alzheimer's get lost in the shuffle? These questions will continue to take on greater urgency as more and more Americans are diagnosed with Alzheimer's. It is estimated that by the middle of the next century, more than 14 million Americans will have Alzheimer's, if no cure or prevention is found.

It is possible that with the proper safeguards, managed care can provide a coordinated approach to care which will be beneficial to Alzheimer's sufferers. What I hope to learn today is how to go about making that possibility a reality. I am so grateful to our witnesses for coming forward today to share their personal experiences. We want to hear about how managed care has worked for you and your loved ones, and we also want to hear where you think the problems and pitfalls are. Your experience is crucial to us as we struggle to find ways to ensure that managed care meets the needs of all of our citizens, particularly those who suffer from degenerative diseases such as Alzheimer's.

The other topic we will be discussing today is coordination of acute and long-term care services. It is no secret that health care in the United States has evolved into a very fragmented system. The nature of the diseases treated, the different types of organizations which provide care, the training of professionals, and the requirements of the various payors have all contributed to this fragmentation. But individuals with Alzheimer's disease would benefit greatly from a more coordinated system. Not only would coordination be beneficial to these individuals, the marketplace will increasingly require it. We need only look at the recent wave of mergers and acquisitions for proof of this assertion. It is becoming clear that in the wake of the managed care trend, organizations which provide acute and long-term care are joining forces to be able to offer a coordinated package. Again, the responsibility falls to us in the Congress to make sure we build adequate safeguards into the system so that the growth of multilevel systems does not become an excuse to offer inadequate or inappropriate care. I am looking forward to hearing from our second panel of witnesses on this topic.

Mr. Chairman, Alzheimer's disease strikes one in ten persons over 65, and nearly half of those over 85. New studies show that Alzheimer's is the fourth leading cause of death of older people in this country. Alzheimer's is the third most expensive disease in the U.S., behind heart disease and cancer. This disease also exacts an incredible human toll—wives who lose their husbands, children who lose a beloved parent, and caregivers who are forced to leave the workplace in order to provide care to their loved one. I want to thank all of our witnesses for being here, and I want to thank you, Mr. Chairman, for holding this important hearing. I know we will all learn a lot today.

The CHAIRMAN. Let me first of all welcome Senator Warner. This, I believe, is his first hearing since joining the Aging Committee.

We're truly pleased to have you with us on this committee, Senator Warner.

## STATEMENT OF SENATOR JOHN WARNER

Senator WARNER. Thank you, Mr. Chairman. You may recall that I served on this committee in years past, and I'm pleased to return.

My father was a medical doctor and often treated persons afflicted with this problem. As I look on my own career, I would have loved to have followed in Father's footsteps, but, regrettably, the good Lord gave me less brains than Father, and therefore I had to accept this lot that I'm in now. [Laughter.]

But I can, whenever the opportunity presents itself, help.

I just had one interesting note. I watched a fascinating piece on television very early this morning of how children should be trained to deal with those in the families afflicted with this disease. It was only about a 5-minute segment, but it was absolutely fascinating—their reaction and their love and their care that they intuitively and instinctively want to provide to the parent or family member afflicted with this disease.

I thank the Chair and the distinguished ranking member, and ask that the balance of my statement be placed into the record.

The CHAIRMAN. Thank you very much, Senator Warner. It will be included in full.

[The prepared statement of Senator Warner follows:]

### PREPARED STATEMENT OF SENATOR WARNER

Mr. Chairman, please allow me to say what a pleasure it is to rejoin the Special Committee on Aging after an absence of nearly 3½ years. I served as a member under the chairmanships of Senators Heinz, Glenn, and Pryor, and I am delighted to now have an opportunity to serve with you.

The Commonwealth of Virginia has a large and growing "senior" population. By the year 2000, we are projected to have more than a million citizens over the age of 65 equaling 15 percent of our total population. This committee provides an outstanding forum for addressing their issues and concerns, and I look forward to again being an active participant.

The topic of today's hearing focuses on the challenges presented to Alzheimer's patients and their families by our changing health care system.

We have all heard a lot about "Managed Care" in the last few years as millions of American workers have been enrolled in various HMO's, PPO's, and the like. It is extremely important that we here attempt to document the record of *long-term care services in the age of managed care*.

Alzheimer's patients and their families face a severe trial because of the severity of the disease. The tragedy of Alzheimers should not be made *even worse* because of gaps in managed care insurance coverage.

Furthermore, with ongoing discussions and proposals to extend managed care options to greater numbers of Medicare and Medicaid beneficiaries, we need to know *beforehand*—as much as we can—how Managed Care affects the quality of long-term care services for the chronically ill.

Mr. Chairman, again, it is great to again be a part of this committee. Later today, I will welcome members of the Virginia Alzheimer's Association to my office, and I look forward to sharing with them the results of this hearing.

The CHAIRMAN. The Aging Committee is honored to welcome our first panel of witnesses.

First we're going to hear from Mr. Tim Ryan, who has been a CBS sportscaster since 1977. He is certainly no stranger to the millions of college basketball fans that recently tuned into the action and excitement of NCAA's March Madness. In addition to covering college basketball, Tim Ryan is the lead CBS sports announcer for the U.S. world tennis and boxing, and was a play-by-play announcer for the women's alpine skiing at the 1992 and 1994 Olympic Winter Games.

For nearly two decades Mr. Ryan has found the words to bring the struggle and thrill of athletic competition to life for all of us, but today his words are going to put a very real face on a different type of struggle—that of an Alzheimer's caregiver.

As a member of the board of the Alzheimer's Association, Mr. Ryan is very active in the fight to find a cure for Alzheimer's and to help find better ways to assist Alzheimer's victims and their family members with the day-to-day challenges this disease poses.

We're also very pleased to have before us today Ms. Lois Rockhold from Mobile, AL, and Ms. Denise Reehl from Gardiner, ME, who are going to discuss their very difficult quest to help their family members who are suffering from Alzheimer's get the kind of care they need. While their situations differ, the huge emotional toll this disease places on those who are closest to its victims reflects the plight of millions of families nationwide.

We're pleased to have Dr. Deborah Marin, the chief of geriatric psychiatry at Mt. Sinai School of Medicine, who will discuss what went wrong with the care that Mr. Ryan and Ms. Rockhold's families experienced and how good clinical care can be provided to individuals who suffer from Alzheimer's disease.

We'll also hear from Ms. Jessie Jacques. Ms. Jacques is a consultant and former administrator of the Alzheimer's Care Center of Gardiner, ME, who will talk about the community services that the center provides to individuals and families such as Denise Reehl's, whose father recently joined the Gardiner Center's adult day care program.

It is always a special pleasure for me to welcome witnesses from my home State, and I'm very eager to hear their testimony and gain some insight into how they've been coping with the problems faced by Alzheimer's victims and their families.

So, Mr. Ryan, if you would begin.

#### STATEMENT OF TIM RYAN, KETCHUM, ID

Mr. RYAN. Thank you, Mr. Chairman and members of the committee.

I do, at the outset, hope that maybe more of the committee will join us as we go along and hear those who follow later who have some very important things to say that affect people like me and Lois Rockhold. I also encourage all of you to feel free to ask questions about anything that I raise in the course of my testimony here, because frequently what is said scratches only the surface, so I encourage you to give me the opportunity to answer any questions you might have.

I appreciate the opportunity to be here today and tell you my story. It's one of at least 20 million horror stories about Alzheimer's Disease, and these are stories that we know about. More than 4 million victims of this killer and at least five times as many more family members are emotionally and financially crippled. How many more go misdiagnosed, undiagnosed, or unreported is impossible to know.

I'm about to be 57 years old. I'm in the prime of my life. My wife Lee won't be 57 until September. She is in a nursing home. I live in a beautiful ski resort. I travel the world as a television sports announcer with CBS. I read books and the latest political news

about you folks. I dine out. I go to the movies. Lee used to do all of those things with me. Now she stares at TV, is unable to speak more than a word or two, needs help eating and dressing. Her longest trip is maybe a walk in the garden, or an occasional ride in the car, usually to a doctor or a hospital.

This is the curse of Alzheimer's. But despite the daily death of her brain cells robbing her of her identity, her memory, her speech, her physical skills, this killer has not yet claimed the beauty of her smile. In her own limited way she is happy most of the time. She's loved and cared for in a special Alzheimer's facility called Villa Bella in Santa Barbara, CA. For the last year and a half I have visited her there every month. For now, she still recognizes me, and greets me with smiles and tears. One of these times she won't.

Still, I consider myself fortunate—fortunate because, unlike all but a fraction of the victims and their families devastated by this disease, I have the means to provide a Villa Bella for my Lee. Most people my age who are dealing with Alzheimer's are trying to help their parents cope with the disease, and at the same time raise their own families. I can't begin to imagine how they ever get through this. Many caregivers are elderly, living on fixed retirement income, many with their own health problems.

Living with Alzheimer's disease is, in a word, a nightmare. As I told "People" magazine in a cover story on Alzheimer's last year, you know the person you love is going to be disappearing before your very eyes. It's truly "the long goodbye."

Allow me to put a face on Lee for you. I asked if I could do this, and they said I could. These are two pictures—one of Lee about 10 years ago and one just last spring. I'd like to briefly tell you the story of how a beautiful, vibrant young woman began to lose her mind, not from psychiatric or emotional causes, but from a relentless attack on her brain cells by a silent killer.

She was not yet 50 years old when the so-called "Early Onset Alzheimer's" began to rob her of her very self. In the spring of 1990 I knew something was drastically wrong. This bright, talented homemaker, tennis player, poet, television producer, skier, and mother of four simply wasn't herself. She was frequently depressed, often confused and forgetful—the opposite of her normally ebullient, organized, and upbeat persona.



Lee Ryan 1955



Rocky 1955



By August we confronted the situation, and that's when her nightmare began. You see, living with Alzheimer's means constantly confronting a health care system that doesn't yet know what to do about the disease or the care of its victims. A kind family doctor conducted fruitless physical and blood tests, ordered a brain scan, referred us to a neurologist whose cursory examination confirmed some confusion but nothing that alarmed him.

Alzheimer's was not even mentioned as a possibility until a neighborhood friend and psychiatrist in our town of Larchmont, NY, recommended a second neurological opinion and raised the specter of a dread disease usually associated only with the elderly.

In January 1991, about 6 months later, not long after a somber family Christmas at our ski chalet in Sun Valley, a top neurosurgeon at Columbia Presbyterian Hospital in New York gave us the stunning news: our beautiful, physically fit, intellectually alert Lee has Alzheimer's disease.

Now what? Getting an accurate diagnosis is a huge problem for many families. Getting good medical care during the inexorable course of the disease can be an even greater challenge.

After immersing myself in material about Alzheimer's, consulting with top researchers, considering experimental drug trials, and meeting with Alzheimer's Association counselors, I faced the fact the best we could do was to manage the disease by providing the best possible environment for Lee's comfort and safety. So we moved full-time to Sun Valley, ID, the town of Ketchum where I, armed with the invaluable support of my four wonderful children and a mantra of patience, strength, and wisdom, and Lee, with a rapidly growing deterioration of her once sharp mind.

Many Alzheimer's victims live for long periods of time in a highly agitated state, especially those with early onset. It takes its toll on the person and everyone around them—even the most patient and loving caregivers.

Certain drugs appropriately used can make all the difference in the quality of life, but some drugs used for extreme agitation, like Haldol, can produce devastating side effects in some patients. We learned that the hard way during our efforts to make Lee less agitated and more comfortable during her limited daily routine of pacing around our house.

After a physical confrontation with a caregiver that she had during my absence during the Olympic games, our well-meaning physician administered a larger dosage of Haldol. It calmed Lee into an almost zombie-like state and produced a horrifying stooping posture that lasted for days until she was slowly weaned off the drug.

Episodes like these can be common until the right combination of drugs can provide some comfort from the stark terror that is the daily staple of an early onset victim.

Very little of the care Lee needs is covered by our health insurance, and getting reimbursed for those things covered in the contract—hospital or outpatient care, doctor treatments or visits, medications—has been a nightmare of its own. I've got a stack of correspondence here that represents about maybe a tenth of the kind of stuff I go through just to get reimbursed for things that are covered in the health plan but are misunderstood.

Alzheimer's-related problems are almost always lumped into the category of "uncovered mental illness," a disgraceful situation unto itself in many health plans.

I noticed on the front page of the "Washington Post" today that finally some Members of Congress are dealing with that aspect.

We hear the same stories from families who are old enough to qualify for Medicare. The intermediaries are refusing to pay for basic health services, either because they consider them mental health services or because they say the patient cannot benefit from them.

Living with Alzheimer's disease also means a constant struggle to find and keep good day-to-day care. People like Lee need constant, 24-hour care. Very quickly they become incapable of expressing themselves, making their needs known, handling personal care—things like toileting, dressing and undressing, brushing teeth and hair. Finding staff for home care became part of our nightmare. Keeping them was more so and paying for them took its own toll.

While Sun Valley is a small, caring community where people reach out to help one another in times of difficulty, it had no in-home care agency when we arrived there in late 1991. Since I travel almost weekly in my job covering sports events, I needed full-time help for Lee. The first two well-meaning folks I hired lasted only a few weeks each. The strain was too much.

When an agency opened in town, I found myself doing the interviewing—an emotionally exhausting and time-consuming task that seldom produced people of quality and with the patience to endure.

Finally, the agency and I assembled a system that worked for more than a year—a team of three women who worked in 2- or 3-day 24-hour shifts. But for all we tried, the inevitable time came when we could no longer provide the care that Lee needed.

In July 1994 facilities were rushing to develop Alzheimer's wings and special care units, but most of them didn't meet the criteria that I had established. For me, the most important thing was to find a place with a staff well-trained in dementia care. That just wasn't there in most of the places that I looked in my area. We wanted a home-like environment, a place with a real personal touch.

When it became clear that we weren't going to find that anywhere close to home, I looked elsewhere. Eventually I found Villa Bella, a small specialized Alzheimer's residence in Santa Barbara, where Lee now lives with 25 other people who have this disease. It is not opulent, but it is homey and well-designed, and the staff knows what they're doing.

Until very recently, Lee was the youngest in the facility by far. She's now just 56, as I mentioned. She has been treated there as a bit of a princess. I know she's getting better care than I would be able to give her at home. I visit, as I said, about once a month, and sometimes our meetings go well, sometimes they don't. But her smile is still beautiful.

Finally, living with Alzheimer's disease for most people means financial ruin. Even the best insurance, including Medicare, does not cover the health care of persons with Alzheimer's needs because it is considered long-term care. I pay \$50,000 a year, including doctor

fees and medication, for Lee's care at Villa Bella. Even when she was home it cost me almost as much, because my job meant I had to have full-time staff available.

In the past 5 years, I have spent about a quarter of a million dollars on Alzheimer's disease. Luckily, I have the resources to do it—at least for now. What in heaven's name do most families do? It's a national disgrace that millions of people in our country are being forced into financial distress because they have to give up jobs to stay at home to care for a loved one with Alzheimer's. Even with decent wages, they can't afford to pay for home health care or nursing home care, none of which is covered for Alzheimer's disease and related disorders.

Most families can only spend what they have, and eventually qualify for Medicaid, and even that degrading door could be closed to them if Congress agrees to some of the most radical ideas about Medicaid that are now on the table, as you well know.

I have a sister in Canada whose father-in-law is an Alzheimer's victim. He's receiving good care in a publicly financed nursing home. I'm not sure that system is right for us here in the United States, but we have to find a way to finance health and long-term care so that a disease like Alzheimer's doesn't bankrupt American care-giving families and spin them into emotional and physical problems of their own.

I determined early on, when this most cruel disease began its assault on my beautiful, youthful Lee, that I would not rage at the gods, and I thought of that again in the last couple of days when I saw Rod Carew's wonderful comments about the loss of his daughter. He said that he was not angry at God for taking her; he was thankful for the time that God had given her here on earth. She was only 18. I'm trying to feel the same way as Rod.

But I do rage at a health care system that does not understand Alzheimer's disease and leaves millions of families not as fortunate as mine in financial ruin and despair. There has to be a better way, and that's why I joined the board of directors of the Alzheimer's Association. That's why I came here to tell you about Lee, show you her picture so you have an idea what can happen to a young person, not just those in the elderly community.

Today more than 400 Alzheimer's advocates from across the country are on Capitol Hill to take to their Members of Congress the Association's 1996 national public policy program to conquer Alzheimer's disease. It's a realistic, affordable plan to deal with this problem through research changes and the health care system and long-term care financing. I'm pleased to deliver a copy to this committee.

Mr. Chairman, under your leadership and that of Senator Pryor, this committee has consistently shone a spotlight on some of the most urgent problems facing older Americans and their families. You've been our consistent allies and champions, and on behalf of the entire Alzheimer's Association and Alzheimer's families across the country, thank you not just for holding this hearing today, but for your steadfast commitment to our cause.

The CHAIRMAN. Thank you very much, Mr. Ryan, for your very moving testimony. [Applause.]

[The prepared statement of Mr. Ryan follows:]

STATEMENT OF TIM RYAN  
KETCHUM, ID  
BEFORE THE  
SENATE COMMITTEE ON AGING  
HEARING ON ALZHEIMER'S DISEASE  
APRIL 23, 1996

Mr. Chairman Cohen and Members of the Committee. I appreciate the opportunity to be here today to tell you my story, one of at least 20 million horror stories about Alzheimer's disease. And these are stories we know about--more than four million victims of this killer and at least five times as many more family members emotionally and financially crippled. How many more go misdiagnosed, undiagnosed or unreported is impossible to know.

I am 57 years old, in the prime of my life. My wife Lee will not be 57 until September, she is in a nursing home.

I live in a beautiful ski resort, I travel the world as a television sports announcer with CBS, I read books and the latest political news about you folks, I dine out, I go to the movies.

Lee used to do all of those things with me. Now she stares at TV, is unable to speak more than a word or two, needs help eating and dressing and her longest trip is a walk in the garden and an occasional ride in a car--usually to a doctor or a hospital.

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Still I consider myself fortunate. Fortunate, because unlike all but a fraction of the victims and their families devastated by this disease, I have the means to provide a Villa Bella for my Lee. Most people my age who are dealing with Alzheimer's are trying to help their parents cope with the disease and at the same time raise their own families. I cannot begin to imagine how they get through this. Many care givers are elderly, living on fixed retirement income, many with their own health problems.

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strength and wisdom", Lee with a rapidly growing deterioration of her once sharp mind.

Many Alzheimer's victims live, for long periods of time, in a highly agitated state. It takes its toll on the person and every one around them--even the most patient and loving care givers. Certain drugs, appropriately used, can make all the difference in the quality of life. But some drugs used for extreme agitation, like Haldol, can produce devastating side effects in some patients. We learned the hard way during our efforts to make Lee less agitated and more comfortable during her limited daily routine of pacing around the house. After a physical confrontation with a care giver during my absence, our well-meaning physician administered a larger dosage of Haldol. It calmed Lee into an almost zombie-like state and produced a horrifying stooping posture that lasted for days until she was slowly weaned off the drug.

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exhausting and time-consuming task that seldom produced people of quality and with the patience to endure. Finally the agency and I assembled a system that worked for more than a year--a team of three women who worked in two or three day, 24-hour shifts.

For all we tried, the inevitable time came when we could no longer provide the care Lee needed. In July of 1994, facilities were rushing to develop Alzheimer wings and special care units, but most of them did not meet the criteria I had established. For me the most important thing was to find a place with staff well trained in dementia care--that just wasn't there in most of the places I looked in my area. We wanted a homelike environment, a place with a real personal touch. When it became clear that we were not going to find that anywhere close to home, I looked elsewhere.

Eventually, I found Villa Bella, a small specialized Alzheimer residence in Santa Barbara, where Lee now lives with 25 other people who have the disease. It is not opulent, but it is homey and well designed. And the staff knows what they are doing. Until very recently, Lee was the youngest in the facility by far, and she has been treated as a bit of a princess. I know she is getting better care than I would be able to give her at home. I visit her about once a month. Sometimes our meetings go well. Sometimes they don't. But her smile is still beautiful.

Finally, living with Alzheimer's disease--for most people--means financial ruin.

Even the best insurance--including Medicare--does not cover the health care a person with Alzheimer's needs, because it is considered long term care. I pay \$50,000 a year, including doctor care and medication, for Lee's care at Villa Bella. Even when she was at home, it cost almost that much, because my job meant I had to have full-time care available. In the past five years, I have spent about a quarter of a million dollars on Alzheimer's disease. I feel lucky that I have the resources to do it. What in heaven's name do most families do?

It is a national disgrace that millions of people in our country are being forced into financial distress because they have to give up jobs to stay at home to care for a loved one with Alzheimer's. Even with a good job and decent wages they can't afford to pay for home-health care, or nursing home care, none of which is covered for Alzheimer's disease and related disorders. Most families confronted with this dilemma can only spend what they have and eventually qualify for Medicaid. Even that degrading door could be closed to them if Congress agrees to some of the most radical ideas about Medicaid that are now on the table.

I have a sister in Canada whose father-in-law is an Alzheimer's victim. He is receiving good care in a publicly-financed nursing home. I am not sure that system is right for us here in the U.S. but we have to find a way to finance health and long term care so that a disease like Alzheimer's does not bankrupt American care giving families and spin them into emotional and physical problems of their own.

I determined early on when this most cruel disease began its assault on my beautiful, youthful Lee that I would not rage at the gods.

But I do rage at a health care system that does not understand Alzheimer's disease and leaves millions of families, not as fortunate as mine, in financial ruin and despair. There has to be a better way. That is why I have joined the Board of Directors of the Alzheimer's Association, and why I came here to tell you about Lee.

Mr. Chairman, under your leadership and that of Senator Pryor, this Committee has consistently shone a spotlight on some of the most urgent problems facing older Americans and their families. You have been our consistent allies and champions. On behalf of all of the Alzheimer families here in this room and across the country, thank you not just for holding this hearing today, but for your steadfast commitment to our cause.



The CHAIRMAN. Ms. Rockhold.

**STATEMENT OF LOIS ROCKHOLD, MOBILE, AL**

Ms. ROCKHOLD. Senator Cohen, members of the committee, thank you for inviting me here today to tell you about my mother, Euleen Tillman.

Mama is 73 years old. She has Alzheimer's disease. Two weeks before Christmas she was living in a small group home in Mobile. Alzheimer's had stolen her memory, but she was still physically strong. She was walking, eating, enjoying afternoons on the front porch with a cup of coffee. On days when I wasn't working, I could bring her home for the day so we could be together. I took her with me to the store. Her life was not at all the same as before Alzheimer's, but there was still some quality to it.

Then, 2 weeks before Christmas, my mother fell and broke her hip. The doctor put her in the hospital and did a hip replacement. He said she was physically strong, and at her age she would certainly walk again. In fact, he said, she might have an easier recovery with the Alzheimer's because she wouldn't remember the fall.

Mama got wonderful care in the hospital. Three days after her surgery, the nurses had her out of bed and walking again. She went to therapy, and we thought she was well on her way to recovery.

After about 10 days they moved her to a nursing home to finish her rehabilitation, and that's when the trouble began.

My mother is in a Medicare managed care plan, Medicare Complete. It cost less than regular Medicare and it seemed to make sense to sign her up for it. We never had any problems with Complete paying her bills. The problem came when they told us there was only one nursing home in town where she could go. We had some concerns about it even then because this was a nursing home that had been shut down by the State, but it was now under new management, it was licensed again, it was clean, and we had no choice.

The nursing home did not have any specialized care for Alzheimer's disease. The staff that took care of Mama didn't understand what the disease was doing to her. There were six of us watching out for her—my four sisters, my brother, and me—but even with all we tried, we couldn't stop what happened.

We would go to visit Mama and find a tray of uneaten food left beside her bed. She hadn't touched it. We kept telling the staff, "Mama can't remember how to eat. She can't do it by herself. You have to help her or give her something she can hold in her hand, like a grilled cheese sandwich, and she'll eat it."

When we were right there, sometimes they would do it, but then the next time we came the tray would be there, nothing eaten. Mama didn't know how to tell them she was thirsty, so she didn't get enough to drink.

She was in that nursing home for rehabilitation to get back on her feet, but the staff said she didn't want to go and they never took her to therapy, so all the progress she was making in the hospital quickly disappeared.

She spent all her time in bed, and bedsores began to show up. Her heels turned black from where she was rubbing them back and

forth on the sheets, and a really bad place showed up on her back. I have some pictures.

Her roommate complained that Mama hollered a lot, but nobody ever took the time to try to do something about it.

She loved to listen to old tapes of religious songs. She remembered all the words to those songs, even though she couldn't remember our names any more and it calmed her down just to have the music playing.

We begged them to play these tapes for her or to keep the television on for company. They never did.

Mama started losing a lot of weight. She went down, down, down. Something had to be done, so 3 weeks after she went to the nursing home, we agreed to let them put in a feeding tube. They took her back to the hospital and we met her there, but the doctor called me aside and said, "Lois, we can't do this. Your Mama's white blood count is over 20,000." The sores on her back were so bad he had to call in a plastic surgeon.

Mama was in the hospital for 2 weeks on IV's to build her up before they could put in the tube. By now it's too late for therapy.

We took Mama back to the group home where she was before all this started. She'll never really be able to walk again. She lives with a feeding tube and a catheter. It scares us so much to think that if something happens to Mama again she'll end up right back there in the nursing home that did this to her. It didn't have to be that way.

I know it's possible to get good care. My sister has a brain tumor. She lives in another nursing home in Mobile, and she gets wonderful care. We wanted to have Mama there because we knew they would take good care of her and she and my sister could be together. They were willing to make a bed for her, but Medicare Complete said no. There was only one nursing home in their plan, and that's where she had to go—no choices.

We even tried to get Mama qualified for Medicaid so she could go to the other home, but the Government makes people crooks and thieves to get into the program. We were willing to use all the money Mama had to pay for that nursing home if the State would just qualify her for Medicaid and get her in, but even with the monthly income of only \$800 the State said that's too much money.

We need to have places like assisted living where people are trained to take care of Alzheimer's patients. Where Mama was, different people came every day. Some of them had never seen a person with Alzheimer's before. You need to have people who know what they're doing and who work with people with Alzheimer's disease every day. We need places with yards where people can get out and walk around and enjoy the outdoors.

Mama was sent to a four-story nursing home on the corner of a busy street. Even if they had tried to get her walking, the only place she would have been able to get any fresh air was to stand in the front doorway.

The public is not aware of the heartache that comes with Alzheimer's. They have no earthly idea what it's like to have your Mama asking for you when you're standing right in front of her and she doesn't know who you are.

Senators I know you can't take the heartache away. That's why we have to keep spending money on research to find a way to stop the disease, but Congress can do something about Medicare and Medicaid to make sure people like my mother get good care and they have the best possible life with this awful disease.

Thank you.

The CHAIRMAN. Thank you very much, Ms. Rockhold. [Applause.]  
[The prepared statement of Ms. Rockhold follows:]

LOIS ROCKHOLD  
MOBILE, ALABAMA

Statement to Senate Special Committee on Aging  
April 23, 1996

Chairman Cohen and Members of the Committee, thank you for inviting me here today to tell you about my mother, Euleen Tillman.

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Then, two weeks before Christmas, my mother fell and broke her hip. The doctor put her in the hospital and did a hip replacement. He said that she was physically strong and, at her age, she would certainly walk again. In fact, he said, she might have an easier recovery with the Alzheimer's because she wouldn't remember the fall.

Mama got wonderful care in the hospital. Three days after her surgery, the nurses had her out of bed walking again. She went to therapy, and we all thought she was well on her way to recovery. After about 10 days, they moved her to a nursing home to finish her rehabilitation. And that's when all the trouble began.

My mother is in a Medicare managed care plan -- Medicare Complete. It cost less than regular Medicare and it seemed to make sense to sign her up for it. We never had any problem with Complete paying her bills. The problem came when they told us there was only one nursing home in town where she could go. We had some concerns about it, even then, because this was a nursing home that had been shut down by the state. But it was now under new management. It was licensed again. It was clean. And, we had no choice.

The nursing home did not have any specialized care for Alzheimer's disease. The staff that took care of Mama didn't understand what the disease was doing to her. There were 6 of us watching out for her -- my 4 sisters, my brother, and me. But even with all we tried, we couldn't stop what happened.

We would go to visit Mama and find a tray of uneaten food left beside the bed. She hadn't touched it. We kept telling the staff, "Mama can't remember how to eat. She can't do it by herself. You have to help her. Or give her something she can hold in her hand, like a grilled cheese, and she'll eat it." When we were right there, sometimes they would do it. But then the next time we came, the tray would be sitting there again, nothing eaten.

Mama didn't know how to tell them she was thirsty. So she didn't get enough to drink.

She was in that nursing home for rehabilitation, to get back on her feet. But the staff said "she doesn't want to go" and never took her for therapy. So all of the progress she was making in the hospital quickly disappeared.

She spent all of her time in bed, and bedsores began to show up. Her heels turned black from where she was rubbing them back and forth on the sheets. And a really bad place showed up on her back.

Her roommate complained that Mama hollered a lot. But nobody ever took any time to try to do something about it. She loved to listen to old tapes of religious songs. She could remember all the words to those songs -- even though she couldn't remember our names any more -- and it calmed her down just to have the music playing. We begged them to play those tapes for her, or to keep the television on for company. They never did.

Mama started losing a lot of weight. She just went down, down, down. Something had to be done. So, three weeks after she went to the nursing home, we agreed to let them put in a feeding tube. They took her back to the hospital and we met her there. But the doctor called me aside and said, "Lois, we can't do this. Your Mama's white blood count is over 20,000." The sores on her back were so bad, he had to call in a plastic surgeon. Mama was in the hospital for two weeks, on IV's to build her up, before they could put in the tube.

By now, it was too late for therapy. We took Mama back to the group home where she was before all this started. She'll never really be able to walk again. She lives with a feeding tube and a catheter. It scares us so much to think that if something happens to Mama again, she'll end up right back there in that nursing home that did this to her.

It didn't have to be that way. I know it's possible to get good care. My sister has a brain tumor. She lives in another nursing home in Mobile and she gets wonderful care. We wanted to have Mama there because we knew they would take good care of her, and she and my sister could be together. They were willing

to make a bed for her, but Medicare Complete said no. There was only one nursing home in their plan and that's where she had to go -- no choices.

We even tried to get Mama qualified for Medicaid so she could go to the other home. But the government makes you crooks and thieves to get into the program. We were willing to use all the money Mama had to pay for that nursing home, if the state would just qualify her for Medicaid and get her in. But even with a monthly income of \$800, the state said she had too much money.

We need to have places, like assisted living, where people are trained to take care of Alzheimer patients. Where Mama was, different people came every day. Some of them had never seen a person with Alzheimer's before. You need to have people who know what they are doing and who work with people with Alzheimer's disease every day. We need places with yards, where people can get out and walk around and enjoy the outdoors. Mama was sent to a 4 story building on a busy street corner. Even if they had tried to get her walking, the only place she would have been able to get any fresh air was to stand in the front doorway.

The public is not aware of the heartache that comes with Alzheimer's. They have no earthly idea what it's like to have your Mama asking for you, when you're standing right in front of her and she doesn't know who you are. Senator, I know you can't take that heartache away. That's why we have to keep spending money on research, to find a way to stop the disease.

But Congress can do something about Medicare and Medicaid -- to make sure people like my mother get good care, and that they have the best life possible with this awful disease.

Thank you.

The CHAIRMAN. Ms. Marin.

**STATEMENT OF DR. DEBORAH MARIN, M.D., CHIEF OF GERIATRIC PSYCHIATRY, MT. SINAI SCHOOL OF MEDICINE, NEW YORK, NY**

Dr. MARIN. Mr. Chairman and members of the committee, I'm delighted to have the opportunity to discuss these particular cases and overall the care for individuals with Alzheimer's disease.

I am a geriatric psychiatrist, and I provide care for patients with Alzheimer's disease and related disorders, and I work very closely with family members of those individuals.

As you can tell from these compelling testimonies, this illness has significant impact on people with the illness and on their families.

Unfortunately, Mr. Ryan's and Ms. Rockhold's experiences are far from unique. Mr. Ryan experienced difficulty in obtaining an adequate diagnosis for his wife. This was, in part, due to the fact that dementias are often considered by primary physicians as only illnesses of old age, and clearly that's not the case.

A specialist in dementia finally, after several months, had made the correct diagnosis. The subsequence of optimal management of Mr. Ryan's wife's agitation is all too common by primary care physicians who may not be aware of the subtleties of new medications available and the specific biological needs of Alzheimer's individuals.

Mr. Ryan then, of course, experienced difficulty in finding the appropriate care for his wife in his home because of the limited insurance reimbursement that he had.

He, fortunately, did have the means to locate, albeit with difficulty, appropriate long-term care for his wife. This is, unfortunately, a typical situation demonstrating the barriers to optimal health care faced by Alzheimer's individuals and their families.

In a perfect health care system, the primary care physician would be able to determine a diagnosis early on and, therefore, would work with the patient and their family for planning in multidisciplinary fashion, including long-term care placement. Day care and long-term care would be reimbursable and also affordable. Unfortunately, we are a long way away from that goal.

Ms. Rockhold's mother had an experience which is not uncommon for Alzheimer's individuals, which was the hip fracture. She subsequently did not receive the continuative health care that would have been essential for her quality of life. Because of insurance coverage limitations, Ms. Tillman then had no choice in her placement, and her subsequent care was clearly not appropriate for her needs. Even an involved family could not change the environment in her care, and the excess morbidity and compromised quality of life sustained by Ms. Tillman are evident.

For Ms. Rockhold's mother, optimal care would have been placement in a facility with appropriately trained staff that could have dealt with not only rehabilitation, but her nutrition needs and her social needs, as well.

Equally important, the family would not have felt adversarial, but rather would have been partners with the health care system.

As has been mentioned already, Alzheimer's disease is a form of dementia that affects not only memory, but also orientation, judgment, problem-solving, and also personality.

Although there is no cure, there are treatments to delay disability, enhance the quality of life, and treat the problem behaviors that so often complicate the illness.

We do know a lot about how to take care of individuals with Alzheimer's disease, and with appropriate care we can reduce their dependency, minimize the impact of the illness on the family, and even save money for the health care system. When caring for an Alzheimer's individual, the physician must optimize medical care for that person. The clinician needs to address medical conditions early on that often complicate the illness. These include: hip fractures, decubitus ulcers, urinary tract infections, malnutrition, and adverse drug reactions, as we've all heard they occur.

Appropriate management of behavioral problems that often occur during the course of the illness must also be performed. Each of these complications, if inadequately treated, can lead to substantial excess morbidity for the patient, burden for the family, and unnecessary cost for both Medicare and Medicaid.

Second, maintaining optimal function is essential for the Alzheimer's individual. The individual should engage in as many physical, intellectual, and social activities as possible.

Third, health care providers need to ensure quality of life. This is very relevant when assessing the quality of long-term care facilities. Measures of quality of life can be obtained from a family and from direct observation. The Alzheimer's individual should show a level of comfort, good hygiene, absence of pain. There should be personalization of rooms and attentiveness on the part of the staff.

For optimal care, the Alzheimer's patient needs to have prompt access to several services, including medical, social work, nursing, day care, home care, and long-term care. In the managed care environment, it is possible to have such a coordination of services, but primary physicians may not always be able to handle all these aspects. As we've heard, dementia specialists may have a key role.

Unfortunately, managed care companies do not provide primary physicians with the incentive to use specialists, or to even treat individuals with chronic illnesses. Insurance companies often do not provide coverage for outpatient home care or day programs.

Given the fact that individuals in their 80's are the fastest growing sector of our society and most likely to develop the illness, it is a health care imperative to offer quality care to Alzheimer's individuals.

In sum, we do know how to provide good care for individuals with Alzheimer's disease and help their families cope. The challenge is to make sure providers are well-trained, that we eliminate barriers to care, and we provide proper financing of quality health services. Thank you.

The CHAIRMAN. Thank you very much, Dr. Marin.

[The prepared statement of Dr. Marin follows:]



**Statement of Deborah B. Marin M.D.  
Bronx Veteran's Hospital and Mount Sinai Medical Center, New York  
Before the Senate Committee on Aging**

Mr. Chairman Cohen and Members of the Committee, I am delighted to have the opportunity to discuss clinical care for individuals with Alzheimer's disease. I am a geriatric psychiatrist. I work at the Bronx Veteran's Hospital and Mount Sinai Medical Center in New York. I provide care for patients with Alzheimer's disease and related disorders in both the outpatient and inpatient settings. I also work closely with family members of Alzheimer's individuals. From the compelling testimonies we have just heard, it is evident that Alzheimer's disease has a significant impact not only on the individual with the illness, but also on their loved ones.

Unfortunately, Mr. Ryan's and Ms. Rockhold's experiences are not unique. Mr. Ryan experienced difficulty in obtaining a timely and appropriate diagnosis for his wife. This was in part due to the fact that clinicians often consider dementias to be illnesses of old age. In fact, at least 10% of Alzheimer's cases occur before age 65. A specialist in dementia eventually made the correct diagnosis. The suboptimal management of Mrs. Ryan's agitation can result from well meaning, but somewhat inappropriate care by a physician who may not know the latest developments in treatment of these symptoms or the special pharmacological needs of the Alzheimer's individual. Mr. Ryan also experienced another substantial barrier to adequate care for his wife because of the limited insurance reimbursement. Mr. Ryan cogently relates the stress, both emotional and financial, that he incurred as a family caregiver. He fortunately had the means to locate, albeit with difficulty, an appropriate long term care facility for his wife. This unfortunately is a typical situation demonstrating the barriers to optimal health care that are

experienced by Alzheimer's individuals and their family caregivers.

In a perfect health care system, the primary care physician would determine the diagnosis early on in the course of the illness. He/she would then work with the patient and family to coordinate care with other disciplines, including social work, nursing, and ultimately the long term care facility. Day care and long term care would be reimbursable and affordable. Unfortunately, we are a long way from that goal.

Ms. Rockhold's mother had an experience with a hip fracture, which is not uncommon in individuals with Alzheimer's disease. She subsequently did not experience the continuity of health care that is so essential for Alzheimer's individuals who experience acute illnesses that complicate the underlying chronic condition. Because of insurance coverage limitations, the patient then had no choice in her placement. Her subsequent care was clearly not appropriate for her needs. The facility did not have the proper resources or staff to care for Ms. Rockhold's mother. Even an involved family could not change this. The excess morbidity and compromised quality of life sustained by the patient were evident. For Ms. Rockhold's mother, optimal care would have included placement in a facility that had an appropriate number of trained staff that would have rehabilitated her to walk again, provided her with stimulating activities, and maintained good physical health through proper nutrition. Equally important, the family should feel that they are partners with, rather than adversaries of, the health care delivery system.

Alzheimer's disease is a form of dementia that affects memory, orientation, judgement, personality, and day to day functioning. It is a chronic and progressive condition that can last up to 20 years after diagnosis. Although there is no cure, there are treatments to delay disability, enhance quality of life, and treat the problem behaviors that often complicate the illness.

We know a lot about how to take care of people with Alzheimer' disease. With

appropriate care, we can reduce dependency, minimize the impact of the illness on the family, and even save money for our health care system.

First, when caring for an Alzheimer's individual, the provider of care must optimize the medical well being of the individual: The clinician needs to address medical conditions that often complicate the illness, i.e., hip fractures, decubitus ulcers, urinary tract infections, malnutrition, and adverse drug reactions. Appropriate management of the behavioral problems that often occur during the course of the illness must also be performed. Each of these complications, if inadequately treated, can lead to substantial excess morbidity for the patient, burden for the family, and unnecessary cost to Medicare and/or Medicaid.

Second, maintaining optimal function is essential for the Alzheimer's individual. The individual should engage in as many physical, intellectual, and social activities as possible. Indices of functional well being include maintenance of the ability to do activities of daily life, continued physical activity, alertness, and the overall quality of social interactions.

Third, health care providers need to ensure a good quality of life. This is very relevant when assessing long term care facilities. Measures of quality of life can be obtained from family members or by direct observation. The Alzheimer individual's level of apparent comfort, hygiene, absence of pain, personalization of the rooms, and staff's attentiveness are all measures of quality of life.

For optimal care, the Alzheimer's patient needs to have prompt access to several services, including medical, social work, nursing, day care, home care, and long term care. In the managed care environment, it is possible to have such a coordination of services. But primary physicians may not be able to handle all aspect of this care. But, as we heard, dementia specialists do have a role and may be invaluable. Unfortunately, managed care companies do not provide primary

physicians with the incentive to use specialists, or to even treat individuals with such a chronic illness. Insurance companies often do not provide coverage for outpatient home care or day programs that could enhance the functional well being of the patient. Given the fact that individuals in their 80's are the fastest growing sector of our society, and the most likely to develop Alzheimer's disease, it is a health care imperative to offer quality care to the Alzheimer's individual.

In sum, we know how to provide good care to people with Alzheimer's disease. The challenge is to make sure providers are well trained, that we eliminate barriers to care, and we provide proper financing of quality health services.

Thank you for inviting me to testify. I am willing to answer any questions.

The CHAIRMAN. Ms. Jacques.

**STATEMENT OF JESSIE JACQUES, R.N., CONSULTANT,  
ALZHEIMER'S CARE CENTER OF GARDINER, ME, UNION, ME**

Ms. JACQUES. Thank you, Senator Cohen and members of the committee, for inviting me to testify on the kind of care provided by the Alzheimer's Care Center in Gardiner, ME.

Since the committee already has my written testimony, I will make just a few remarks which I feel are important.

The special care center in Gardiner is a 30-bed facility which offers residential care long-term, in-house respite 1 to 6 weeks, Alzheimer's day care, and coordinates three support groups for family members and the community.

Even though I worked in institutional long-term care for about 28 years, I believe it is most important for older people, including those with dementia, to stay in their own homes as long as possible. But when that is no longer an option, there should be alternate choices which allow these people to have quality and dignity in their lives, and choices which give the caregiver much-needed relief from their 36-hour days.

The Alzheimer's Center in Gardiner is a unique, home-like model project 8 years old which emphasizes socialization and activity in a secure setting and provides a very important continuity of care.

Those individuals who use our day care program and go home with their families at night to familiar surroundings often utilize the respite bed, and when the time comes for admission to the residential care program, this is accomplished with little or no trauma to the resident or family.

This program is also heavily involved with education and training of health care providers and the community, at large. Education must play an important part in all of this, and probably should be the first and foremost responsibility of those of us involved in dementia care.

In summary, there are programs like the Alzheimer's Care Center which are successful, but there are not enough of these. We need more dementia-specific units at the residential care and nursing home level, more help in the home, and more integration of all the above.

Thank you for the privilege of bringing this information to this hearing.

The CHAIRMAN. Thank you very much, Ms. Jacques.

[The prepared statement of Ms. Jacques follows:]

## United States Senate Special Committee on Aging

April 23, 1996

Testimony of Jessie E. Jacques, R.N., Consultant

THE ALZHEIMER'S CARE CENTER, GARDINER, MAINE

## A MODEL PROGRAM THAT WORKS

Senator Cohen and members of the committee, thank you for the opportunity to present testimony today regarding the needs of people with Alzheimer's Disease and their families, and to tell you about a program which has been addressing these needs for the past eight years.

I have worked in long term care for 28 years and for the last eight years have been the administrator of a Special Care Unit for dementia residents in Gardiner, Maine. This facility was the first of its kind in the United States and has been used as a model for others. The building was designed and built from the ground up specifically for persons in the mid-stage of Alzheimer's Disease (or a related dementia) who meet state regulations for admission to a Residential Care Facility.

This 30 bed home offers 29 beds for long term care (usual length of stay is 2 - 2 1/2 years); one bed for In-House Respite for one to six weeks; and an Alzheimer's Day Care Program which presently consists of 23 clients and has an average daily attendance of twelve, Monday through Friday from 7:00 a.m. until 5:30 p.m. The Day Care clients/participants are integrated into the total program of the Center and receive all available services, and are then able to return to their own homes where the surroundings are familiar.

An important consideration in caring for Alzheimer's folks is "continuity of care." This continuity is achieved at the Center where Day Care, In-House Respite, and Residential Care (long term) are offered. Residents and families who have participated in the first two programs experience very little trauma when the resident is admitted to the Residential Care Program. Unfortunately, this facility does not have a nursing home component on the grounds, but that care is

available within the system and elsewhere in the community.

The philosophy of care at the Alzheimer's Center is based on the fact that the quality of life for persons with Alzheimer's Disease can definitely be improved by a program which emphasizes the importance of socialization in a secure facility, carried out by a knowledgeable staff, who have a dedicated interest in the residents.

The primary tool used to maintain and enhance quality of life is a well-organized activity program which provides opportunities for everyone to participate in exercise groups, musical events, art therapy, outside trips, household chores, etc. -- all which increase self-esteem, sense of belonging and dignity. The Center has also strived for and achieved a feeling of "hominess" -- of being "at home" within its walls, which is a valuable and important item in any successful endeavor of this type.

Because Alzheimer's affects the entire family, every special care unit for dementia residents must try to meet caregivers' needs by educating them about the disease and its progression; by providing legal advice, and by directing them to all available resources. This is accomplished at the Gardiner Alzheimer's Center and similar programs through Support Groups. The Gardiner Center coordinates three of these which meet monthly. Also, the Alzheimer's Association with its many chapters across the country is the best resource for all of the above and has been for some time.

The Alzheimer's Center in Gardiner is also very much involved with training and educating caregivers in the community and institutions throughout the State of Maine.

In my 51 years of involvement with health care, which started in 1945 during World War II when I was a paid Nurse's Aide, I have witnessed much sadness, but there have been no situations or stories any more heartbreaking than those experienced by caregivers of Alzheimer's victims who have lost their loved ones to this disease which ravages the mind and then, years later, the body, after devastating the caregiver family. The effects of this disease have been literally "brought home" to me since my own father suffered from Multi-Infarct Dementia and my partner's mother died only last year from Alzheimer's Disease.

In summary, I would like to say that there are programs which do work for the reasons already mentioned, but there are very few of these special units in existence, and that in the State of Maine, as elsewhere, we need more funds appropriated for special care units for dementia; for more nursing home beds and residential care beds for dementia victims; for more help in the home for these folks and their families, and for more training and education for all, and that these programs need to be integrated as completely as possible.

The Alzheimer's Care Center in Gardiner, Maine, is an example of one program which has succeeded in recognizing the needs of Alzheimer's victims and their families, and you will hear from one of our family members, Denise Reehl, whose father is in the Center's Day Care Program and on the Residential Care waiting list. I think you will know after listening to her how important this type of care is to all those in need of help.

Thank you.



The CHAIRMAN. Ms. Reehl.

**STATEMENT OF DENISE REEHL, GARDINER, ME**

Ms. REEHL. Thank you, Mr. Chairman and members of the committee.

I'm currently—

The CHAIRMAN. Before you begin, I would like to just note for the record how brief those witnesses are from Maine. That's typical. [Laughter.]

Ms. REEHL. I'm currently caring for my father, who is 82 years old and in the beginning to intermediate stages of Alzheimer's. I first began to notice that things were not quite right about 4 years ago right after my mother passed on, but it wasn't obvious until about 2½ years ago that this was more than the effects of grief.

About that time my dad stopped calling me regularly. Being 350 miles apart—he in Albany, NY, and myself in Gardiner, ME—we used to call each other quite regularly. He would always say he would call, but then he would never do it. He had gone out or he had forgotten or he claimed that he had called.

Well, one day when I couldn't get through to him at one point because of a busy signal, I called a neighbor and left a message to have him call me. In fact, his phone had been disconnected because he had forgotten to pay the bill.

When I got down there, indeed, much more was amiss. I discovered a tax lien on the house, garbage piled everywhere, and loose cash sandwiched between magazines. He had no car insurance, his personal hygiene needed attention, and he looked thin—very thin.

Eventually, he developed pressure sores on his feet, but claimed to have arthritis. I never checked his feet because I thought he must know.

Then, one time when I was cleaning up around the house, I came upon a slip of paper on which was written a recent diagnosis given by his family physician, "Alzheimer's disease, early to intermediate stages."

A phone call to his doctor indeed confirmed this, and a trip to the neurologist reconfirmed it. He, however, was in denial.

My father was very good at making believable excuses and covering up with humor and misdirection, and I wanted to believe that the man who had taken such good care of his loved ones was still capable of carrying on, as always.

I wanted to respect his independence, and I also secretly dreaded the thought of taking over every detail of his life.

I live with my husband and two children, ages 13 and 15. I'm self-employed with my husband.

As it turned out, it was necessary for me to bring my dad to my home under the guise of a visit. Once I got him out of his home I thought, "Well, everything will fall in place," but, in actuality, it was just the beginning of this very long journey.

My father requires constant cuing all day long. He needs to be reminded that it's time to bathe, what clothes to be put on, and when it's time to take his medicine, that it's time to eat—yes, that he has read the paper today, and that it's Tuesday or Wednesday or Friday. He often awakens not knowing where he is and asks me how he got there.

He is otherwise physically well and can often carry on very lucid conversations, and just when I think this man is just fine, he'll tell me all over again exactly what he just said.

He hoards his belongings, he's convinced he has no money and constantly asks when he'll be going home. He also denies that anything's wrong with him because he feels good.

I can remember one conversation, in particular, when, after I had explained—I thought quite clearly—that he must stay with me now, he looked me straight in the eye and he said, "I understand perfectly the situation," and I was elated. I thought, "Wonderful. I got through." But when asked the next day if he remembered anything about that conversation, he said very cagily, "I haven't given it much more thought." Then, when I pressed that point, he said, no, indeed, he did not remember what we had spoken about, and we were back to square one.

Since then I've had many conversations like that, all forgotten. The exasperation level is very high on both sides. My family has been compassionate and supportive throughout this ordeal. My dad has been with us for 4 months now, and every day my husband and I ask each other, "Do you really think we can do this?" It's been especially hard on him because he essentially has lost his work partner, me, and carries on for the time being without me.

Our children are learning the true meaning of compassion, patience, tolerance, and selflessness at a time when they're also struggling just to learn about themselves.

The angry outbursts and displays of frustration by my dad have severely tried us all, and while living this nightmare in paralyzed silence we grieve the loss of the man we love.

It's not easy to explain what's going on in our family to friends who never knew my father when he was whole, and it's just as difficult to those who knew him well.

The assumptions and misunderstandings run rampant, and, above all, an Alzheimer's patient and his loved ones cling to their dignity.

For me, the most difficult pieces of this puzzle have been first of all accepting the reality of parenting my parent, and then overcoming the myth that somehow I'm deceiving him by not always insisting that his perceptions are not real. To him, they are very real.

Unlike the previous witnesses, I am fortunate enough to live down the street from an Alzheimer's care center. It has been like a cup of cold water to a weary traveler. The staff doesn't pretend to have all the answers and, in fact, openly admits that dealing with Alzheimer's is the ultimate in improvisational theater, which ironically is my line of work. They have been patient with my denials, my misgivings about my abilities and my frustrations.

In the spirit of a true friend, they have listened, shared their experiences, lent a shoulder to cry on, and encouraged me to go on. They've been there to assure me that what I'm feeling is normal, and have helped to relieve the tremendous guilt of having to make very difficult choices.

Most importantly, they have provided care for my loved one, as I would.

My father is on the waiting list for residential care there and is currently enrolled in the day care program two afternoons a week.

During that time, I know he's safe and cared for, and I can recharge my batteries for the ongoing challenge. Without those 10 hours a week and my many consultations with staff members, I don't think I could have come this far.

I am currently in search for part-time care-givers to come to my home and provide some relief for my family from this burden, but I am not hopeful, and I really don't know where to begin. As Mr. Ryan stated, the energy that takes is exhausting.

I also attend support group meetings where families share their insights and help each other somehow get through all this. Meeting the financial and emotional needs of long-term care can be devastating to any family. I don't know how long my dad will be able to stay with me or how we'll fare financially—he has no long-term care insurance—but I do know that my gratitude for the encouragement and counseling I have received from the Alzheimer's center is unbounded, and I'm sure I speak for many others who have had to live this very long goodbye.

Thank you.

The CHAIRMAN. Thank you very much. [Applause.]

[The prepared statement of Ms. Reehl follows:]

TESTIMONY OF  
DENISE REEHL OF GARDINER, MAINE  
before the  
United States Senate  
Special Committee on Aging  
April 23, 1996

Good Morning, Mr. Chairman and members of the Committee, my name is Denise Reehl. I am currently caring for my Father who is 82 years old and in the beginning to intermediate stages of Alzheimer's Disease. I would like to thank you for inviting me here to tell our story.

I first began to notice that things were not quite right about four years ago right after my mother passed on but it wasn't obvious until about 2 1/2 years ago that this was more than the effects of grief. About that time my Dad stopped calling me regularly. Being 350 miles apart, he in Albany, NY and me in Gardiner, Me., we always stayed in touch by phone twice weekly. He would always say he would call but somehow never did. He had gone out or had forgotten or claimed in fact that he had called. When I couldn't get through to him at one point because of a busy signal all day I called a neighbor and left a message to have him call me. In fact, his phone had been disconnected because he had forgotten to pay the bill. When I got down there indeed much more was amiss. I discovered a tax lien on the house, garbage piled everywhere and loose cash sandwiched between magazines. He had no car insurance, his personal hygiene needed attention and he looked thin--very thin. Eventually he developed pressure sores on his feet but claimed to have arthritis--I never thought to look at his feet. I figured he would know. Then one time when I was cleaning up around the house I came upon a slip of paper on which was written a recent diagnosis given by his family physician--Alzheimer's Disease--early to intermediate stages. A phone call to his doctor indeed confirmed this.

My father was good at making believable excuses and covering up with humor and misdirection and I wanted to believe that the man who had taken such good care of his loved ones was still capable of carrying on as always. I wanted to respect his independence and also secretly dreaded the thought of taking over every detail of his life. I live with my husband and two children, ages 13 and 15, in Maine and am self-employed with my husband. As it turned out it was necessary for me to bring my Dad to my home under the guise of a "visit". Once I get him out of his home, I thought, the rest will fall into place. In reality, of course, this terrible debilitating journey has just begun.

My father requires constant cueing--all day long. He needs to be reminded that it's time to bathe, what clothes to put on, that it's time to

take his medicine, that it's time to eat, that yes, he has read the paper today and that it is Tuesday or Wednesday or Friday. He often awakens not knowing where he is and asking how he got here. He is otherwise physically well and can often carry on lucid conversations. Just when I swear this man is alright, he'll tell me all over again exactly what he just said, as if he never said it before. He hoards his belongings, is convinced that he has no money and constantly asks when he'll be going home. He also denies that anything is wrong with him because he "feels good". I can remember one conversation in particular when, after I had explained very clearly, I thought, that he could not live alone anymore and must stay with me now, he looked me straight in the eye and said, "I understand the situation perfectly". Yes! I thought--contact! But when asked the next day if he remembered anything about the conversation the night before, he cagily said he hadn't given it much more thought. Eventually, it became apparent that the answer was no. We were back to square one. Since then there have been many conversations like this one--all forgotten. The exasperation level is high on both sides.

My family has been compassionate and supportive throughout this ordeal. My Dad has been with us for four months now and every day my husband and I ask each other, "Do you think we can do this?". It's been especially hard on him because he has essentially lost his work partner and carries on for the time being without me. Our children are learning the true meaning of compassion, patience, tolerance and selflessness at a time when they are also struggling to learn about themselves. The angry outbursts and displays of frustration by my Dad have severely tried us all. And while living this nightmare, in paralyzed silence we grieve the loss of the man we love.

It is not easy to explain what is going on in our family to friends who never knew my Dad when he was "whole" and it is just as difficult to explain to those who knew him well. The assumptions and misunderstandings run rampant and above all, an Alzheimer's patients and their loved ones cling to their dignity. For me, the most difficult pieces of this puzzle have been first of all accepting the reality of parenting my parent and then overcoming the myth that somehow I am deceiving him by not always insisting that his perceptions are not real. To him they are.

The Alzheimer's Center in Gardiner, Me. has been like a cup of cold water to a weary traveller. The staff doesn't pretend to have all the answers and in fact openly admits that dealing with Alzheimer's is the ultimate in improvisational theater (Ironically, my line of work). They have been patient with my denials, my misgivings about my abilities to do this and my frustrations. In the spirit of a true friend they have listened,

shared their experiences, lent a shoulder to cry on and encouraged me to go on. They've been there to assure me that what I'm feeling is normal and have helped to relieve the tremendous guilt of having to make very difficult choices. Most importantly, they have provided care for my loved one as I would.

My Dad is on the waiting list for residential care there and is currently enrolled in the daycare program two afternoons a week. During that time I know he is safe and cared for and I can recharge my batteries for the ongoing challenge. Without those ten hours a week and my many consultations with staff members I don't think I could have made it this far. I also attend support group meetings where families share their insights and help each other somehow get through this. Meeting the financial and emotional needs of long term care can be devastating to any family. I don't know how long my Dad will be able to stay with me or how we will fare financially. He has no long term care insurance. But I do know that my gratitude for the encouragement and counseling I have received from the Alzheimer's Center is unbounded and I'm sure I speak for many others who have had to live this very long goodbye.

The CHAIRMAN. Thank you very much, Ms. Reehl.

I think this has been perhaps one of the most moving panels which has ever testified before the committee. My one regret is there is not a single network camera here to record your poignant testimony. We have the written press here, and they will cover it in some detail, but there is no substitute for millions of people having access to the stories which you have told.

Unfortunately, we're competing, apparently, against term limits on the Senate floor, or perhaps an investigation into who wrote *Primary Colors*. But it does get a little bit frustrating here to try to structure a hearing so that millions of people can watch and learn and lobby. This is another very important aspect of it.

Mr. Ryan, if I could ask you, you just heard Ms. Reehl's testimony about the signs that she recognized from her father. What was the first thing that you started to notice about your wife that called your attention to the fact that perhaps she should seek some kind of a diagnosis? What were the symptoms?

Mr. RYAN. Senator, I guess that's the most commonly asked question, because it represents a certain fear, obviously, on your part and for all of the people around you: what do I look for? I think the other question most often asked is not so much a question but an observation, "My god, how could that happen to somebody so young?" We think that's for old people. Obviously, we've discussed that.

To answer your question, I think the things that I noticed first were, to give specific examples, somebody who was so highly organized and ran the social calendar for us—if we were having dinner with friends the next night, it was always on the calendar, and I relied on her to say, "What are we doing this week? Are we going to see the Joneses or the Smiths? Or let's go to a movie, or whatever." She would always have that right on the money, and you grow to rely on that in a partnership of marriage.

Suddenly things were not there. Somebody would call and say, "We'll meet you at the theater," or what have you, and I'd say, "What? I didn't know we were doing that tonight." I would ask Lee, and she would be defensive about it—a form of denial that just didn't recognize that she wasn't up to speed the way she had been.

The most crucial moment for me occurred in May of that year, of 1990, when she was doing her accounting for the tennis league for which she was the treasurer—the local tennis league she played in—and she was just filling out a deposit slip of the club's dues from the various clubs in the area, and she was in tears at the dining room table trying to fill out this deposit slip of maybe 25 or 30 clubs and that many entries, obviously.

I asked if I could help, what was the problem, and she was just completely confused and had written down several of them two or three times, and I knew that something was drastically wrong.

But, as I said in my testimony, Alzheimer's certainly didn't occur to me. I mean, we're talking about a 50-year-old woman. I knew very little about Alzheimer's in 1990. It was things like that that just grew in proportion until finally, by August, we sat down and I said, "Honey, there's something going on here. Is it me? Have I done something to change our life?" Consequently, we went from there to get further diagnosis.

But there are a number of things. I think usually confusion and forgetfulness are the things you notice first.

The CHAIRMAN. Excuse me, Mr. Ryan. I know that Senator Craig has another commitment, so I'd like to yield my time to him so he can ask a few questions before he leaves.

Mr. RYAN. Certainly.

Senator CRAIG. Mr. Ryan, first of all let me thank you for being here and obviously adding a dimension to the concern and the awareness of this disease that many of us are generally unaware of as it relates to younger people.

In your struggle to find a care facility—and while we've heard testimony from several today who, fortunately enough, are finding care, and others who did not—in the western part of the United States where we both live, there were no facilities that could handle this particular difficulty in Idaho?

Mr. RYAN. Well, I wouldn't go so far as to say that. I indicated in my testimony that I had established kind of my own set of criteria.

Senator CRAIG. That's fair enough.

Mr. RYAN. There were nursing homes in Twin Falls and in Boise which, as you know, are communities not too far away from where I live.

Senator CRAIG. Right.

Mr. RYAN. I started there, of course. Your first instinct is to do something close to home. Clearly, there was no facility in Sun Valley or Ketchum, a small community, including Hailey, of less than 15,000 people. But what I saw there was the beginning of these special care units, and they were essentially a wing of an existing nursing home facility turned into a so-called "special care unit." That's not to knock their effort. They were trying.

Senator CRAIG. Yes. That was not the thrust of my question. Rather, I'm just curious about the availability of specialized care in our State and region. Is this a growing care capability, or is it still very difficult to find?

Mr. RYAN. Well, I think in the last 5 years that there is plenty of evidence that everywhere in the country there's much more awareness and much more effort being made by nursing homes to create special homes unto themselves. There are many more of them now than there were then. Villa Bella, which I found, was one of the few even in California, a much larger State with many more facilities.

I found nothing like that in our immediate area, Boise being obviously our largest city to draw on. I did look at a half a dozen there, and nothing approaching what I ultimately found.

Senator CRAIG. Thank you.

Thank you, Mr. Chairman.

The CHAIRMAN. Mr. Pryor.

Senator PRYOR. Thank you, Mr. Chairman. I apologize, too. I'm going to have to leave. I'm glad our colleague, Senator Grassley of Iowa, is here with us now.

You know, I think I have seen a figure somewhere, Mr. Chairman and colleagues, that about half of the nursing home residents today in America are there because of either Alzheimer's or a related mental disorder, a dementia of some sort. And in keeping



with the recent question and the answer by Mr. Ryan, I don't think that most—I would say I don't think that 95 percent of the nursing homes in America today are qualified, truly qualified, to deal with Alzheimer's patients. [Applause.]

Senator PRYOR. Let me say this. I've been a severe critic of nursing homes in the past, and will perhaps continue. I don't know. But I'm not sure it's all of their fault. I think it's a lot of our fault. I think we're not furnishing the carrot and the stick to give them the incentive to go out and train their personnel as to what's going on, what to expect, how to treat these patients. Second, I'm not sure that we are putting the proper emphasis on mental disorders as we grow older as a general rule.

We're really unqualified. We're not prepared for this. I think we've got to start rethinking how we're going to deal with this enormous problem that seems to be growing.

I hope I can come back for the second panel and ask this question, because I always do: is Alzheimer's something that I've just started hearing about in the last 7 or 8 years? It seems like now every other older person I know has Alzheimer's. I didn't hear about Alzheimer's a decade ago, before I came to the Senate, but now it is everywhere.

I hope one of our experts in this field will be asked such a question.

I think we've got to do better about preparing our nursing homes out there.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you.

Senator Grassley, would you like to make a statement or ask some questions?

Senator GRASSLEY. I'd like to ask questions.

First of all, I apologize because I did not hear your testimony. I was at the Judiciary Committee meeting. I wanted to be here because I have people from my State visiting me this afternoon on this subject. They may very well be in the audience now.

I remember holding a hearing in 1983, when I was Chairman of the Aging Subcommittee of the Senate Labor and Human Resources Committee when there wasn't a lot of talk about Alzheimer's disease at that particular point, and holding that hearing was a real educational experience for me.

I compliment Senator Cohen for keeping the issue very much alive—not that we have to worry about the issue dying or getting out of people's mind, because there are more folks connected with it all the time, but to talk about the quality of life for Alzheimer's victims, when probably 13 years ago we would have been spending time in the committee just bringing attention to the issue. There has been some advancement on the subject.

I know that the testimony this morning was very moving, so I compliment you for participating in that.

I would ask Ms. Jacques: one of the things that I know you had in your testimony probably bears repeating and emphasizing, and that was that the quality of life for people with Alzheimer's disease can be improved. I know that there is no one on the panel that thinks otherwise, and particularly people in the audience who are family members of somebody with Alzheimer's disease would agree.

But some people, without much experience of the disease, may think that it doesn't make any sense to worry about the quality of life of Alzheimer's victims, given the nature of the disease, so I wonder if you might just comment on that point about whether or not the quality of care of Alzheimer's victims can be improved, and if it is improved, the extent to which that helps with a lot of other aspects of that person's well-being, physical and otherwise.

Ms. JACQUES. Well, I have seen the quality of life improve in many of the residents who have been in our care at the Alzheimer's center in Gardiner. That is certainly not to say that the disease is cured or even slowed down, but through efforts in activities planning—which includes exercise groups, music groups, gardening, all kinds of special visits to the outside—and particularly those group activities to which the residents can relate, subjects are discussed which would have been very much a part of the lives of our residents 40 or 50 years ago.

Music is played that brings back long-term memories. When the Alzheimer's residents participate in dancing or singing—and they do remember the words to all the old songs—when they discuss flat irons and washboards and all kinds of things, they feel much better about themselves.

When certain games are played that they can take part in, they feel as though they are taking part in life.

We're very much involved with household chores, things that are very special to folks in Maine. They feel as though they've accomplished something. Their self-esteem is increased. Their behavior improves. Therefore, there is an increased quality to their lives.

Senator GRASSLEY. On another point, Dr. Marin, in your testimony you made several references to the role of family and stated that family should feel that they are partners rather than adversaries of the health care delivery system.

In your position as a geriatric psychiatrist, obviously you work closely with many family members of Alzheimer's patients. I'm sure you understand, as do many of people here today, the important role that families can play.

From your perspective, could you elaborate on the important roles of families in caring for an individual with Alzheimer's disease, and particularly comment on the advantages or disadvantages of the current system in respect to family involvement and the care of Alzheimer's patients?

Dr. MARIN. Sure. As was already stated actually by Senator Cohen, the majority of individuals with Alzheimer's disease and other dementias are cared for in the home, and the statistic probably is closer to what Mr. Ryan said. It costs about \$50,000 a year to keep a person either in a home or in a nursing home—it doesn't matter. So families are definitely an integral part in treating these individuals.

On the same note about the quality of life, there have been studies with family members that have shown that if the family member is taught how to handle the patient, how to understand what's going on with the illness, and cope better themselves, that actually leads to less institutionalization of Alzheimer's individuals.

The family members can play a critical role if they are given an opportunity to learn from the health care system. They can't do it

on their own. There have to be programs out there that can help them, and there are pilot programs like that.

So I think in this era right now, the family also is the advocate for the Alzheimer's individual. The Alzheimer's individual cannot advocate for themselves, even at the earliest stage of the illness. They are a surrogate who are seeking care and obtaining care from all levels in terms of good dentition, nutrition, a good place for the person to live, finding good care at home. The family member is the key to good care for the Alzheimer's individual at this point.

In terms of access to care and in terms of what's going on now, I think that rack over there shows how—I find it confusing, and I run three member disorders programs. Who does a family member turn to and when? How does health care get delivered? It's exceptionally confusing because the way the system is designed now there is no clear path of entry. There is no clear point of entry and then a serial stage of steps to pursue thereafter.

The Alzheimer's Association probably is the largest organization in the States that helps family members maneuver through the system. The system is not set up to teach families how to do it on their own, though.

Senator GRASSLEY. Thank you, Mr. Chairman.

[The prepared statement of Senator Grassley follows along with prepared statements of Senator Kohl, Simpson, and Reid]

#### PREPARED STATEMENT OF SENATOR CHARLES GRASSLEY

Mr. Chairman, thank you for holding this hearing. I've learned through my own efforts with respect to Alzheimer's disease going back to the 98th Congress what a terrible thing it is for those struck by it and what a terrible thing it is for their families. So the more attention we can bring to finding ways to cope with it the better, as far as I am concerned.

Your hearing this morning is very appropriate in light of the movement by Medicare and Medicaid into managed care. In Medicare currently, I understand that about 9 to 10 percent of beneficiaries are enrolled in managed care plans.

Now, 10 percent does not seem like a lot. But enrollment in these plans is growing rapidly. The day almost certainly will come when far greater numbers will be enrolled in such plans.

The Balanced Budget Act the Congress sent to the President last year contained a Medicare reform which would have given Medicare beneficiaries greater choice of health plans, including managed care plans. If this reform had been enacted, it is safe to say that it would have resulted in more Medicare beneficiaries enrolling in some form of managed care.

I believe that the Administration also supports Medicare reform. Clearly, there are differences between the approach laid out in the Balanced Budget Act and the Administration's preferred approach. But, as a consequence of both Congressional and Administration's interest, I think you'd have to say that some sort of Medicare reform will eventually occur. Those reforms will probably result in more Medicare beneficiaries enrolling in managed care plans.

We therefore need to get a better understanding of how these plans provide care for the seriously ill and for the chronically disabled, such as those with Alzheimer's disease. We need to do so now, for the sake of people already enrolled in such plans, as well as for the greater numbers who will be enrolled in them in the not-so-distant future.

Just one final point, Mr. Chairman. We can certainly all understand the potential for managed care for people with chronic diseases. However, if there is an incentive to underserve in managed care systems, as they currently work, as there seems to be, it seems clear enough that the chronically ill will not only not be well-served, but will be avoided. Your hearing can help us begin to come to grips with this problem. I hope the committee under your leadership will continue to develop this issue.

## PREPARED STATEMENT OF SENATOR HERB KOHL

Mr. Chairman, thank you for holding this hearing.

At some point in our lives we all have to face the inevitability of growing older or come to grips with the aging of a family member. Many difficult challenges may then ensue. For some, this can be a graceful process and a chance to celebrate a lifetime of memories; for others, it is a period where memories vanish and meeting medical costs becomes a daily battle.

Unfortunately, for those with chronic illnesses and their family members, this battle can lead to emotional and financial ruin. The reality of Alzheimer's disease is particularly harsh as the victim's memories fade, health complications grow and family members are forced to witness the degeneration of a loved-one. Since there is no cure, families can only try to make life as comfortable as possible for those in their care.

At least 4 million Americans suffer from Alzheimer's disease. Unless we find a cure, 14 million people will have the disease by the middle of the next century. The cost of this disease is equally staggering. The average lifetime cost per patient is \$174,000. The cost to our society is approximately \$80-100 billion each year in medical expenses and lost productivity.

As Members of Congress, and as a society, we must strive to find ways for all Americans to lead a graceful life when they are stricken with Alzheimer's disease or other chronic ailments. Because of growing costs that will accompany the aging of our population, we must also develop long-term care systems that are cost effective. These are the ultimate challenges we consider today.

We won't resolve these challenges in this hearing, but we will take strides in the process by covering two important issues relating to Alzheimer's disease: how Alzheimer's patients and their families receive care in the current fragmented health care system; and how our long-term care system can be improved to better care for patients with dementia and other chronic illnesses.

The sooner answers are found to these questions, the sooner families will be able to provide compassionate care for their loved-ones, and the sooner Congress may develop policies to effectively deal with the Nation's long-term care needs and accompanying costs.

Thank you, Mr. Chairman. I look forward to today's testimony.

## PREPARED STATEMENT OF SENATOR ALAN K. SIMPSON

I thank Senator Cohen for convening this hearing on Alzheimer's disease. He is a very caring and compassionate man and a fine friend. This is one of those problems that we, as legislators, cannot address in a thoughtful manner until we have listened carefully to the family members of those who are afflicted.

It is always helpful to hear from policy analysts and the experts who write "white papers"—and their advice is certainly worthy of our consideration—but it is the families of Alzheimer's patients who we can learn most from. They are the ones who know from personal experience just how truly horrific and debilitating and cruel this mysterious disease is.

As the son of a wonderfully spirited man who lived with Parkinson's disease for over 30 years, I believe I can emphasize with our panelists. While Parkinson's and Alzheimer's are surely different in various respects, the families of those beset with these diseases are affected in similar ways. Securing access to the proper care and treatment is not in any way a clearcut or easily defined process. There is no manual to follow, nor is there any precise set of rules by which to proceed.

Adding further to these challenges are the changes that are taking place as our health care system continues to evolve in response to market pressures. The growing prevalence of managed care is a reality we must adjust to. Even in the frontier State of Wyoming, we are seeing a steady movement toward some form of managed care. Rather than viewing this movement with suspicion or dread, we should consider the potential of managed care plans for responding to the unique problems and special requirements of Alzheimer's patients. I am pleased to hear that some of our panelists will comment on these opportunities later this morning.

We must also focus our attention on the issue of personal responsibility. For those who have the wisdom and the means to purchase it, long-term care insurance is an important protection that is enormously beneficial in the event of a chronic illness. Just last week, during the Senate's consideration of the Health Insurance Reform Bill, we approved an amendment that makes long-term care insurance tax-deductible to the same extent as other health insurance costs. This is a very important step toward making such insurance more affordable.

The stark truth is that there are limits to what Medicare and Medicaid can do. As health care entitlements devour an ever larger portion of the Federal budget with each passing year, it becomes more and more apparent that Medicare and Medicaid cannot "do it all." Personal responsibility must be a part of our overall strategy for assuring that Alzheimer's patients receive proper care and treatment.

Again, I thank our distinguished Chairman for holding this hearing. I look forward to hearing from the panelists who sit before us.

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#### PREPARED STATEMENT OF SENATOR HARRY REID

Good morning Mr. Chairman. I would like to thank you for scheduling this hearing at a time when the Alzheimer's Association is holding its 8th annual forum here in Washington. It is always nice when such an opportunity presents itself. This year's conference, with the theme "Building the Future," has successfully brought over 500 individuals together to continue vital discussion on various aspects of coping with this disease. I am delighted that we could hold our hearing during their annual conference and very pleased to see that so many of them were able to be present as our committee discusses this very important topic today.

Since we've last held a hearing on Alzheimer's disease, there has been much activity in the field. While there is still no cure for this debilitating disease researchers are beginning to make very real advances. I firmly believe that continued research, and efforts to increase public awareness on this disease, are needed to bring even greater attention to this illness and its impact on both the Alzheimer's patient and the families of the patient. The results achieved in the past few years are encouraging but we must not stop until we've found the cause and developed the cure.

As you know Mr. Chairman, currently an estimated 4 million Americans suffer from Alzheimer's. Lifestyle improvements and advances in medical technology in the decades ahead will lead to a significant increase in the number of people at risk for Alzheimer's. Unless medical science can find a way to prevent the disease, delay its onset, or halt its progress, it is estimated that 14 million Americans will have Alzheimer's disease by the year 2050.

I'm pleased today that we will address the impact this disease places on both the patient and their families. Caring for a person with Alzheimer's can be emotionally, physically, and financially stressful. It is estimated that the annual cost for caring for an Alzheimer's patient is \$47,000. The average lifetime cost per patient is \$174,000. Overall, the disease costs the Nation between \$80-100 billion a year in medical expenses, round the clock care, and lost productivity.

In my home State of Nevada, a woman who heads the Northern Nevada Chapter of the Alzheimer's Association Mrs. Norah A. Brennan, knows first hand about the financial and emotional costs of caregiving responsibilities. Her husband had the disease for over 16 years, the last ten of which he had been in a group home or skilled nursing home. Mrs. Brennan absorbed 100 percent of the cost for this treatment. Fortunately, she was among the few in this country who can afford to pay on their own. Care for her husband cost over \$200,000. Due to the progression of his illness she was no longer able to provide this critical care at home as his needs became too great. In her current capacity as president of the Northern Nevada Chapter of the Alzheimer's Association she works with many families trying to care for their loved ones at home. The caregivers she works with are often seniors in their 70's and many times are not in the best of health themselves. They may have a monthly income of \$2,000 per month, making too much for Medicaid and too little to afford putting their loved one in a skilled nursing facility. The caregiving options available are directly related to one's ability to pay for care. This is perhaps the greatest dilemma a family faces when Alzheimer's strikes their loved one.

In that so much of the care for a patient diagnosed with Alzheimer's is provided by family members and friends due to the high costs of skilled facility care, another critical concern I have is ensuring sufficient resources are available to ensure caregivers are trained on proper techniques and procedures to care for patients with Alzheimer's. At some point, a person with Alzheimer's will require 24-hour care, including assistance with daily activities such as eating, grooming and toileting. We must ensure that the network to provide this care is available, well trained and affordable.

As I mentioned earlier, the financing of care for Alzheimer's is by some estimates as high as \$100 billion each year. The Federal Government covers \$4.4 billion and the States another \$4.1 billion. As you can see, the greatest burden to pay for this care are borne by patients and their families. It is therefore appropriate that our committee focus on their plight as well.

I am also pleased that we will address the impact of managed care on treatment for a patient with Alzheimer's. We owe it to our Nation's elderly to ensure that as our health care delivery systems evolve, we are responding to the medical realities and illnesses presented by patients in a fair and just manner. It is therefore appropriate that we examine how managed care provides services and support to those stricken with Alzheimer's disease.

Mr. Chairman again let me thank you for scheduling this important hearing. I look forward to the testimony of the witnesses this morning and remain encouraged by the developments made in the field over the past few years. I truly hope that the breakthrough needed to uncover the cause and ultimately the cure for this disease is within our reach.

The CHAIRMAN. Thank you, Senator Grassley.

Mr. Ryan, let me come back to you. We talked about the first symptoms that you started noticing. You brought your wife to a doctor for examination or diagnosis, and he did not diagnose the condition.

Mr. RYAN. No.

The CHAIRMAN. Correct?

Mr. RYAN. That's correct.

The CHAIRMAN. Was it because of the age factor, namely that your wife was so young?

Mr. RYAN. I think so. Yes. This was a family doctor and a family friend, and a very distinguished physician in his field of internal medicine in New York. But because we were also friends, we spoke on a more personal basis than the clinical basis. It did not occur, certainly to me as a layman, nor to him as a doctor, that this could possibly be Alzheimer's.

Clearly, he went very quickly to a neurological examination after he had done his usual physical and blood tests, but even the first neurologist gave her a simple test. He said, "Yes, there are a few things here that she seems to be a little confused about," but he didn't twig on it either, to use an expression. Of course, now you're just more worried. What else can it be? So you do an MRI for a possible brain tumor.

Eventually, as everybody in this room knows, it's a process of elimination. You ultimately arrive at Alzheimer's because you haven't found anything else, and even then, clinically speaking, that's not an official diagnosis. If it's written properly it will say "probable Alzheimer's." You don't know for sure until autopsy.

The CHAIRMAN. Ms. Rockhold, did you ever think about complaining to the nursing home staff, the physicians associated with it, maybe the State ombudsman, about the treatment that your mom was receiving?

Ms. ROCKHOLD. Yes, we did. As a matter of fact, I had served in the Legislature in the State of Alabama and knew the nursing home association people and called and complained, and they never got back. But we are following up on the problems that she had. They send you to this person, to the other person.

The thing that bothered us so bad was that the person over this Medicare Complete, we were told by the second nursing home, who had the authority to sign a contract to allow us to take Mama somewhere else, but because this was the one that they had chosen to use, they would not allow us to do that.

We tried to pay them everything that Mama had to put her in this nursing home if they would just assure us that, once we had spent everything, that she could go on Medicaid and that we could

be assured of that, because with all of us working it would be devastating to try to pay for this. So we did everything that we could. We went to the top, and we're still pursuing some avenues on it.

The CHAIRMAN. When you say your mother had bedsores, that sounds like a small, little problem, but we've had—

Ms. ROCKHOLD. I have some pictures for you to see.

The CHAIRMAN. I want to see the pictures and have them distributed to the Members.

We've had testimony before, when you're talking about bedsores, how truly outrageous they can be. It seems to me that those kind of photos have to be brought to the attention of State legislators, as well. When a certain home is designated as the only qualified nursing home to deal with this type of patient, something is wrong.

Ms. ROCKHOLD. If my mom had any idea I was here with these pictures, no way. But you can see how she came back.

The CHAIRMAN. We've been debating the issue of nursing home standards. Senator Pryor and I, for example, have been resisting the notion that, if we're going to try to deal with Medicaid by turning more of the responsibility over to the States—the States say, "Cut the strings. If you're going to give us block grants, we want less regulations." The one thing we have insisted upon is that we maintain some level of Federal standards for nursing homes. [Applause.]

The Governors come back to us and say, "Look, we're just as concerned as you with respect to the treatment of our citizens, so don't pretend that you're more concerned than we are. We can handle the issue." But we can go back and show the history behind the nursing home situation way back in the 1960's and the 1970's.

There has been great progress made, tremendous progress made, and nursing homes have, indeed, come way up in their standards, but we don't want to see a return to the past. We don't want to see the kind of pressure that's going to be generated upon the States as far as their dealing with Medicaid patients and then start lowering the standards or having the standards and not enforcing the standards, which is just as bad as having no standards at all. That's one thing we want to be very sensitive to as we deal with the whole reform of Medicare and Medicaid.

Dr. Marin, what kind of questions do you ask a physician? Suddenly your loved one is diagnosed with Alzheimer's. What kind of questions would you recommend that we ask if we're family members? Are there drug therapies we should be seeking out?

I have a letter here. I'm going to introduce it into the record in a moment. It's from a friend of mine, Don Larrabee, who used to be the president of the National Press Club and covered me when I first came here in 1972, and has submitted a letter to me because his wife, who is a very close friend of mine, as well, had Alzheimer's and just passed away a few weeks ago.

In his letter I'm going to read just a couple of quick paragraphs. He said, "At this point—" after she had been diagnosed with Alzheimer's—"I welcomed a call from the National Institutes of Health asking if we would like to participate in a protocol involving a new potentially helpful drug to deal with Alzheimer's. She willingly made the trip to Bethesda three times a week to receive the medication and submit to all manner of spinal taps, brain scans, as well

as memory tests. After a few months, the funding for that program ran out, and I assume the drug is no longer being pursued."

One of the big problems that we have right now is that most of the scientists who have come before this committee have indicated we are real close, we are very close to having breakthroughs in dealing with Alzheimer's and other types of brain diseases.

What we need to do is put a little bit more money up front. We will save what? The studies show—[Applause.]

The studies show that if we delay the onset of symptoms for 5 years, it's \$50 billion a year. So here we are quibbling about a few dollars up front, when the big savings are to the entire country.

Thanks to Senator Hatfield and others, in a period of time in which we're cutting back dramatically in terms of spending, he has, in the resolution, increased spending at NIH about 5.7 percent in funding for research. So we are still making some real progress as far as forcing ourselves to put the money up front in terms of research so that we can save billions of dollars as far as treatment is concerned.

You can also realize savings with stroke. If we delay the onset of stroke, it's another \$15 billion saved; Parkinson's, \$3 billion.

So we're talking about being very close to having enormous breakthroughs in drug therapy, and that's something that I would think that anyone who finds their spouse or parent or loved one who is now diagnosed asking, "Doctor, are there any therapies out there that are available and, point two, that I can afford?" That's point two that we'll deal with in a moment.

What would you recommend, Doctor?

Dr. MARIN. You make wonderful points. We are an academic center at Mt. Sinai and we do conduct research; however, research, unfortunately, is only for a very few people because they may not qualify for it.

So the first thing—I'd like to back-step a moment—actually, I think Mr. Ryan's case is a really salient example. If you have a loved one who has memory problems and the doctor says, "I don't know," then you don't even have a diagnosis. You have to pursue it very actively, and the family member must do that and the family member should say to the doctor, "No offense, Doctor. I'd like a second opinion. I'd like the name of the major academic centers that have memory programs." That's the first step in the diagnosis, because all too often people are diagnosed with this illness a 1½ years to 3 years after the symptoms have been apparent.

Older adults frequently are afraid of mentioning this problem to their loved ones or to their families, so the first thing of being an advocate is getting up front with the doctor early on in the disease diagnosis.

Once a diagnosis is made, I think it is incumbent on the family and the physician to sit down and have the family member with the illness part of the discussion of what's going to happen. They have their own opinions, as well. That's the next step.

After that's done, the family should sit down and discuss what are the treatment options in terms of what we call "cognitive enhancement." There is an FDA-approved medicine available, and the doctors should give information on that in a non-judgmental fashion. There are pros and cons. It's called Cognex.



Then, in terms of the behavior issues, the family must say, "What else happens aside from memory? What goes on with this illness?" The doctor should—if they cannot provide the information, which often they do not even have the time to, they should hook the family up with either a social worker or a service in their area—a local chapter of the Alzheimer's Association—because the family must become educated early on in the illness to understand the myriad of cognitive thinking changes and the behavior changes.

Included in that is financial planning, home care issues, issues of supervision of the patient. Those are early steps. But you can't—as I said before, it's really critical. There has to be some outside agency, be it either philanthropic or people may pay for it, who can help the family navigate through these multifactorial decisions early on.

They should ask about research, I think, absolutely. If the physician doesn't know, I guarantee you the local chapter of the Alzheimer's Association would know which centers in the area—there are 30 Alzheimer's centers around the States that are funded by the National Institute of Health and Aging. They do a lot of work and there are very good programs by drug companies, as well. So if the doctor doesn't know, the family should advocate to find out where they can go to get the opinion for eligibility of studies.

The CHAIRMAN. What was your reaction to Ms. Reehl's story about a doctor diagnosing her Dad with Alzheimer's who lived alone? I mean, don't we have to do a little education here as far as the medical community is concerned? Is there a problem with—[Applause.]

Dr. MARIN. Absolutely.

The CHAIRMAN. Had not the phone been cutoff for lack of payment, Ms. Reehl wouldn't have known initially for some time. Is there, from a physician's point of view, is there a problem with privacy issues that a physician cannot disclose a diagnosis to other members of the family unless that person gives permission?

Dr. MARIN. There is a raging debate about this in terms of privacy. The issue about Alzheimer's is that if, for example, the Alzheimer's individual drives, privacy becomes almost a moot point because you're allowing somebody with impairment and judgment of thinking to go out and possibly kill themselves or hurt others.

So there is no necessary consensus opinion, although I think that the majority of academic centers would say that if an individual is diagnosed it is the ethical responsibility of the caregiving center to contact a family member, because it's not a private issue once a diagnosis is made.

The legal issues, the financial issues, and the safety issues are robust with this illness. It's possible that the family physician did not know, or the patient may have said, "I do not permit you to give my diagnosis to my family," and that becomes an issue of the contract of confidentiality, and then I think the physician must work with that patient to buildup trust in the relationship so that people can be brought in.

There are professional agencies that can be brought in short of the family, anyway, like mobile crisis units.

The CHAIRMAN. Of course, you can buildup trust 1 day and lose it the very next day with a patient, right?

Dr. MARIN. Absolutely. That's why oftentimes you actually need mobile crisis units to go in and make assessments.

The CHAIRMAN. Ms. Jacques, I have visited your facility, and I'd like to engage in a promotional advertisement for it. It is one of the finest facilities I've ever seen. You have an absolutely wonderful atmosphere. It's bucolic and, except for a tough winter during the course of a few months, the people there are able to get out and enjoy the outdoors. Nature is all around them. It is really a truly wonderful program.

But I'm wondering, are you unique? Is anybody else in Maine doing what you're doing, or anyone throughout New England? Mr. Ryan had to go to California to find something comparable, I assume. How do we find places like what you're doing? Or should nursing homes have some kind of a comparable facility as part of the long-term care aspect of dealing with this?

Ms. JACQUES. There are very few across the country, but there are some, and some of them have used us as a model. There are now about four or five residential care dementia facilities in Maine. Yes, definitely nursing homes need these special dementia units, and they need a lot of help with that, and they need a lot of education.

The CHAIRMAN. How many people do you have there?

Ms. JACQUES. How many people do we have from Maine?

The CHAIRMAN. No. How many people are residents at the center.

Ms. JACQUES. Thirty.

The CHAIRMAN. What about a waiting list? Have you got a long waiting list?

Ms. JACQUES. Between 45 and 50 at present. Our beds are always full. There is a tremendous need.

Senator GRASSLEY. Mr. Chairman, I have a follow-up on that very issue.

The CHAIRMAN. Sure.

Senator GRASSLEY. I was going to ask you a similar question. You have these special units for dementia. Is there some sort of standard that—professional standards that you have to qualify to have one of these units, so that the person that has them just doesn't advertise, "We have this special unit for Alzheimer's victims," and that it would mislead the public that they're not getting certain care that they would expect from some special care unit?

Ms. JACQUES. Well, the criteria at the Gardiner unit are, No. 1, that the resident has to meet State standards for residential care. They have to be self-ambulatory, able to help with some of their own activities of daily living. We do require a visit to a geriatric evaluation unit to establish a diagnosis of Alzheimer's or related dementia.

Does that answer your question?

Senator GRASSLEY. No. I'm talking about the unit, itself, and the people that would—in other words, if I read in the paper that a certain residential facility has a special care unit for Alzheimer's victims, can I know by reading that there is something really extra special there? Does it have professional standards that it has to meet to qualify?

The CHAIRMAN. In other words, is there any truth in advertising as far as nursing homes are concerned.

Senator GRASSLEY. Yes. That's another way of saying what I'm up to.

Ms. JACQUES. To begin with, it doesn't have to be a specially designed facility. A successful special care unit for dementia folks can certainly be accomplished within a nursing home. But there has to be the philosophy, there has to be freedom so these folks can move around, there has to be—there have to be a lot of special programming things.

Senator GRASSLEY. Are these fairly standard from one part of the country to the other, or even within one State? You said you have few units in Maine. Are they pretty much the same in Maine, as an example?

Ms. JACQUES. I think we all have the same basic philosophy. The buildings are all different. Some are better than others, I'm sure. But we're really—this is still in its infancy.

The CHAIRMAN. Thank you, Senator Grassley.

Just a couple more questions. You've all been very patient. We've spent quite a bit of time with this panel, but it's important for everyone to hear your experiences.

I'd start off by saying, "Blessed are the caregivers." I don't think most people have any idea of what you have to go through in dealing with an issue like this.

Ms. Reehl, you talked about your dad's stubborn pride. How many of us don't have parents or have had parents who are absolutely stubborn and don't want to disclose any vulnerability whatsoever?

I had a dad who passed away this past year. He worked 18 hours a day 6 days a week, all on his feet. I noticed one day when I went home that his feet were swollen up almost like elephantiasis, and I said, "Dad, what's the problem?" He said, "I'm on my feet all day. I've just got to take a little bit more rest, sit down once in a while. No problem."

Of course, I came back here and said, "Something's wrong. That's not just normal swelling. That's really swollen." Of course, he had congestive heart failure and was not going to admit that he had a problem.

We all have parents who want to demonstrate to their children or wives or to their husbands that they remain as sound and healthy and vigorous and vital as when we first knew them and last knew them.

It's a real tough struggle for the caregiver to deal emotionally with the issue.

I think there is another portion of the letter I want to quote from, Don Larrabee. He said, "My own experience was a happy one in the circumstances." I think it was 5 or 6 years that MaryBeth suffered from Alzheimer's. He said, "I can't help but feel that, lacking a cure for Alzheimer's, which is still far in the future, the best medicine is a comfortable home environment in which the caregiver is able to enjoy regular intervals of relief."

This perhaps is the biggest thing that we can do—find a way to give the caregivers a break. You mentioned, I think, the 36-hour days, Ms. Rockhold. Maybe it's 48 hours a day in which the

caregiver feels that they are carrying this weight. We don't have a program for providing this kind of relief. You do, Ms. Jacques, by having a day program where Ms. Reehl can bring her father and get some relief, go to work, deal with her creative talents, and now you, Mr. Ryan, obviously, with being able to have your wife in a comfortable setting.

But for most people, who can't afford that, who have to deal with it in a home environment, there has got to be an absolute tangible atmosphere of not quiet desperation, but pretty loud desperation and anger and irritation.

I think most people are in need of counseling. They need counseling to get through it, and we don't have anything for them. So that's the reason why I thought that we should have greater discussion and visibility of this issue. This is something, as those charts indicate, if you get to be 85—and more and more of us are going to be 85. If you look at the demographics, those over 65 will double in population in the next couple of decades. Those over 85 will double in population, and one out of every two over 85 is going to have Alzheimer's, so the numbers are overwhelming when you look at them.

We don't have—and this is something that you testified to, Mr. Ryan—we don't have a system capable of even dealing with this now, not to mention what's coming in the future.

Mr. RYAN. I think I'd like to make one comment, something that struck me last week in terms of long-term care and the cost of it and the insurance companies making it so difficult by not providing coverage for pre-existing conditions.

Watching the Oklahoma City anniversary, Governor Keating of Oklahoma was talking about people whose families have been affected, injuries, etc., since that time, and that they were maxed out on their health insurance. So now an effort was being made on the part of the public and the State of Oklahoma to help these people with the rest of their medical costs, which will continue until they're well again.

Watching that on television I said, "Boy, it would be great to, in the next sound bite here, see the president of one of these insurance companies stand up and say, 'Hey, we're here to help. Because we realize this is an unusual, difficult situation, these people should not have to worry about being maxed out. We'll extend their insurance. We'll lose a little bit of money here in order to help these people.'"

So, while we're here lobbying the Senate and your committee, I think it's also incumbent on all of us to be lobbying and pressuring the insurance companies here. If they were selling cars, they would make an effort to continue selling cars. They would reduce the prices, if necessary. They would take a little bit of a hit. That's the way American business works.

But insurance companies seem to be exempt from this kind of thinking, and I'd like to see some of the pressure applied on them, as well. [Applause.]

The CHAIRMAN. I wish CBS or one of the networks were here to record your remarks.

Mr. RYAN. I'll work on it.

The CHAIRMAN. All right. Well, before I dismiss this panel, I want to call attention to Ms. Shelley Fabares, who is the star of "Coach." She is well known to this committee. She testified here a couple of years ago on this very subject matter. She's also on the board of the Alzheimer's Association. Also Steve McConnell, who once served as staff director of this committee under Senator John Heinz; and also Judy Riggs of the Alzheimer's Association. I want to welcome all of you here and thank you for your participation and help in putting this committee hearing together.

Now I'm going to release this first panel so you can go back to your tasks and we'll call panel No. 2.

Thank you very much for some very informative testimony. [Applause.]

Next we're going to hear from several witnesses who will share their expert knowledge on the health care system. We're going to discuss the opportunities, and the potential problems, the growth managed care will have for people with chronic illnesses. They will discuss the complexity of the current health and long-term care system and why integrating services and providing patient-centered case management can lead to better and more cost-effective care.

The committee welcomes: Stanley B. Jones, the director of the Health Insurance Reform Project at George Washington University; Griff Steinke Healy, chairman of the Alzheimer's Association; Edith Eddleman Robinson, the director of social medicine at Kaiser Permanente Medical Care Program in Los Angeles, CA; and Dr. Cheryl Phillips-Harris, who's the clinical resource director in the Continuing Care Division at Sutter/CHS in Sacramento, CA.

We appreciate all of you being here today.

Would you begin, Mr. Jones.

**STATEMENT OF STANLEY B. JONES, DIRECTOR, HEALTH INSURANCE REFORM PROJECT, THE GEORGE WASHINGTON UNIVERSITY, WASHINGTON, DC**

Mr. JONES. I thank you for the chance to present these ideas to you. In addition to my work in the policy field in Washington, I'm an Episcopal priest in the diocese of West Virginia and work with caregivers' programs in the State. We work with volunteers in assisting people with Alzheimer's and other chronic conditions, and this is a subject dear to my heart.

I'd like to start by saying that managed care obviously offers great hope, given the confusion portrayed in a chart like that shown to the committee. Any management or coordination of services has got to be a help, given that level of complexity.

In addition, the idea of paying providers on a capitated basis so that they have more flexibility for tailoring their services to the needs of individual patients is a great advantage of a managed care system.

However, there is a problem, and it's a problem that's especially important in our Medicare program, in the way we pay health plans, which doesn't provide incentives to insurers or managed care plans to provide quality care to chronically-ill people. It simply doesn't provide business incentives to provide good care to chronically-ill people.

In fact, at best, health plans have to be ambivalent about people with Alzheimer's or who are chronically ill with a number of other costly conditions. When I say ambivalent, I mean that they don't want to market them. If they enroll people with those costly conditions, it has the effect of pushing their average costs up and pushing up their premium. You know this as the problem of adverse risk selection.

This drives plans to a strategy which I characterize as "staying in the pack." You don't want to be noticeably better than your competitors, lest you attract more than your share of these costly subscribers. You don't want to be scandalously worse so that the bad publicity hurts your enrollment; but you don't want to be noticeably better.

In fact, some plans are more sophisticated than that and pursue what you'd have to call a "back of the pack" strategy: try not to be scandalously bad, but, for heaven's sake, be the last choice rather than the first choice of people who have these conditions.

The CHAIRMAN. Would you describe it as being strategically mediocre?

Mr. JONES. That's not a bad description for some plans.

Now, there are all kinds of plans out there, and one of the mistakes we make is talking about managed care as though they are all the same when, in fact, there are marvelous plans and there are plans that are really very poor.

But even a good plan that develops a better way of taking care of Alzheimer's patients or chronically ill people better not advertise it. If you go to the managers of such plans and say, "Isn't it true that your clinicians are doing wonderful things for certain chronic conditions, and creating more satisfaction for the patients and the family. Why don't you describe this in your open season brochure, and why aren't you out there on the television saying, 'Enroll in our plan for this condition because we can do the best for you'?" The answer is that it would be suicide to do that.

The CHAIRMAN. Tell me why that is so. Why couldn't you have a situation where you offer yourself as the best in the business, you are the Michael Jordan of health care plans for Alzheimer's? Why wouldn't that draw in not only the most severe cases but the well-to-do as well that are healthy saying, "Hey, I want to be with the best? I want to go watch Michael play? I want to be part of the team? I don't want to be the second team. I don't want to play for the Bullets. I don't want to whatever?"

I don't mean to disparage the Bullets. [Laughter.]

You know what I'm suggesting.

Mr. JONES. I know what you're getting at.

The CHAIRMAN. Why can't you advertise yourself as the best in the business and therefore draw not only the sickest and those with the most severe problems, but those who are healthy, as well.

Mr. JONES. It's a good question, and you would hope that the market would work that way, and the market usually does work that way. Generally, if a service company finds a better way to provide a service, if it invests money in exploring it, developing it, and making it work, then the company markets it to increase its market share. That's why companies invest capital—in order to increase their market share.

The fact is, in the insurance business, if you attract those folks with Alzheimer's and other high-cost, chronic illnesses, it's going to push your premium up, and the people who are healthier are going to find other choices during open season at a lower price.

People who are chronically ill get to be very knowledgeable purchasers of health care. They talk to other people with the same illness. They find out who the best providers in town are, and they know who they want. Health plans can also learn that and know that if they sign up those providers they're going to get those patients, and if they get those patients as subscribers their premiums are going to go up. Their competitor, their competing health plan, who doesn't enroll those providers and doesn't enroll those patients, will have a lower premium. Healthier people will gravitate toward the lower-premium plan.

It's a market failure in our competitive health insurance system. It really is. In this age of talking about markets and how we'd like them to work to help us, this is a market failure. You have providers who'd like to sell their services to this population—good providers who'd like to say, "Come to us; we can do the best job." You have educated consumers who'd like to seek out and find the best providers and in the middle you have health plans who, at best, have to be ambivalent about both those consumers and those providers who are favored by them.

It's a market failure. It results in exactly the kind of stories you've heard this morning. It results, from the chronically ill standpoint, in not being able to get at the doctor that everyone says is the best for your problem, or not being able to get the service that people say you should be getting.

Maybe you end up with a nursing home, as we heard earlier, that you really don't want, when you know better exist in the community.

This market failure also results in no advertising. If you're going to find a health plan for your chronic illness, you'd better be prepared to do the research because you'll not see anything on television from health plans or in their brochures that tell you they're the one that's best for you.

It also results in health plans simply being slow to get the claims paid. You have this sense they don't really want you in this plan, and your sense is correct.

In the long-term, the prospect of our current market failure is even scarier. Plans don't have an incentive to invest in improving the clinical care to these populations. We're used to a health care system that has invested in making clinical care better. That's not the case with health plans.

Over the long term, they can not increase market share by investing in care to the chronically ill, their incentive is to stay in the pack.

The CHAIRMAN. What happens when the scandal really hits home? If you've got the kind of numbers that are coming like a tidal wave now on the health care system, and everyone says, "We really don't want to attract these," what do we do with them?

Mr. JONES. I think what we'll get is a "floor" that regulation ends up establishing plans you have to do at least this floor; or private credentialing agencies like the National Commission on Quality

Assurance will establish floors that you have to at least do this much as a plan.

But the fact is, those floors are likely to be minimal and difficult to police, and the business incentives in the system don't push plans to exceed those floors. They don't reward plans for doing better.

They'll meet the floor, because no one wants to be hurt by a scandal, but they won't really compete to do better than what we've heard is being done this morning. In other words, we're fighting the business incentives.

I think we can do better than that. I think Medicare can do better than that. What we need to do is purchase from health plans in a way that, in fact, rewards them, gives them business incentives for improving the quality of care to the chronically ill.

There are a variety of approaches to this. Medicare needs badly to experiment with these. As an example, you might, in this marketplace, go to those providers who find themselves insulated from chronically ill patients by health plans and ask the providers, "Why don't you form a plan and bid? Tell us how much you would charge to provide comprehensive services to these populations who are diagnosed with these kinds of conditions?" Then we can take those bids, and when people are diagnosed with these conditions, they can choose between staying with their existing plan or, switching into one of these special centers.

By paying what's fair for this condition, we'll get providers who will invest the resources to improve care to them and even advertise to recruit them.

There is a market there. It's just that the way that we've structured the incentives right now is blocking it from being effective.

Medicare needs to pursue these options. They need your pressure and interest to move in this direction more quickly. They may need some additional demonstration authority.

The CHAIRMAN. As I indicated, we did include ten demonstration projects in the balanced budget, which was then vetoed. Hopefully we'll come back to it when we get to budget consideration.

Mr. JONES. Very good. Thank you.

[The prepared statement of Mr. Jones follows:]



SENATE SPECIAL COMMITTEE ON AGING

HEARING: April 23, 1996

ALZHEIMERS AND OTHER CHRONIC CONDITIONS UNDER MANAGED CARE

Testimony:

Stanley B. Jones, Director  
George Washington University Health Insurance Reform Project

Mr. Chairman:

It is a privilege to testify before the committee.

My purpose today is to draw your attention to a serious problem for chronically ill people, and I think for all of us, in Medicare. The problem exists in every health insurance arrangement where multiple health plans compete for the same enrollees. As you know, in many areas of the country Medicare currently offers HMOs to beneficiaries as an alternative to the traditional program. In addition, Medicare is experimenting with offering preferred provider organizations as choices; and legislation passed by the congress last year would further expand these choices.

The problem is that health plans do not want to compete to attract chronically ill people who are likely to incur high health care costs. The plans have a good reason. If they attract more high cost enrollees than do other plans, their premium is likely to rise higher, and they are likely to be less successful.

Because of this problem of "adverse risk selection," health plans have very strong incentives not to invest resources and effort in offering improved care to the chronically ill. In fact, when it comes to chronic illness, the strong incentive for health plans is to "stay in the pack," that is to be regarded as no better and not scandalously worse than their competitors.

This situation is an example of "market failure" in this age when everyone wants markets to work to contain costs and assure quality. Nevertheless, there is a strong market among the chronically ill for good health care to keep them as healthy and functional as possible. If a health plan were to invest in improvements for the chronically ill and advertise them, they would get customers. People who are chronically ill are

sophisticated buyers. They have to be. There is also a strong interest among clinicians in offering services to these patients, especially clinicians who have excelled in providing care to the chronically ill. They would be delighted to be part of a health plan that wants to go after the chronically ill market.

So we have chronically ill buyers on the one hand, and providers of care on the other who are anxious to sell to them. But in between we have health plans who don't want to do much business with either. (See the attached chart) Even if a plan has found ways to offer better care to the chronically ill they already enroll, they can't afford to advertise such improvements. It would be suicidal. No matter how efficient you are, the costs of most chronically ill people are still be well above the costs of your average enrollees and will therefore raise your premiums to everyone. You can't afford to enroll more than your share.

Health plans can do much better by investing their capital and marketing efforts to attract less costly enrollees. It does not make business sense to invest capital in improving your product and performance in areas where you can't market yourself.

Now there is a quick but unworkable answer to this problem circulating on capital hill. It is included in almost every legislative proposal. It suggests we vary the premium we pay to health plans to reflect the number of sicker people they enroll. For example, if a health plan were to enroll more Medicare beneficiaries with Alzheimers disease, Medicare should increase the premium payment to them in order to cover those higher costs. Similarly with other costly illnesses. This method is usually called a premium adjustor for risk selection.

The problem with it is that risk adjustors don't resolve risk selection well enough to encourage plans to invest in improving care to the chronically ill and marketing to them. I am submitting for the record a paper I have recently released

reviewing the research on the subject. Suffice it to say that while we can and should adjust premiums as best we can for risk selection, we are no where near being good enough at it to actually encourage health plans to compete to attract the chronically ill. Given the best we know how to do, health plans will remain at best ambivalent about the chronically ill.

Stop and reflect for a moment on what this means for the chronically ill and for the Medicare program. We are accustomed to thinking doctors and hospitals will invest talent and resources to improve health care to people who are very sick; and to bring the latest medical advances to them; to find ways to care for them better and make them more functional.

I am afraid we are moving into a period of stagnation in our effort to improve care to the chronically ill. A period when the chronically ill person finds health plans:

Do not offer the physicians they think are best,

Hold back on new procedures,

Make it difficult to get referrals,

Do nothing to publicize their strengths, and

Offer increasingly lackluster care.

For Medicare it means spending taxpayers dollars for such lackluster care. It also can mean higher costs for Medicare, as plans avoid chronically ill patients and leave them to remain in the traditional Medicare program.

As the purchaser of health plans on behalf of taxpayers, Medicare has the same right and obligation as large employers to assure their money is being well spent and the plans they offer

provide good value to the beneficiary. In this market oriented era in health care and in federal policy, we need to find ways Medicare can purchase so as to make the market work better for the chronically ill, such as people with Alzheimers disease.

One step is to set standards for health plans that require some basic level of performance with regard to the chronic illnesses most common in Medicare. These might be modeled after the credentialing standards used by private credentialing organizations - but should be developed with the assistance of experts in the various illnesses so as to define observable practices that constitute a minimum requirement for all plans under Medicare. I'd like to see the Alzheimers association and others devote themselves to developing such standards.

But a further and more promising step is also possible. We can offer to pay a fair price to groups of providers who are willing to better organize and manage care to beneficiaries with specific chronically illnesses. We could even ask groups of providers to bid to offer comprehensive care to beneficiaries with specific diagnoses for a capitation payment. When a beneficiary is diagnosed with a chronic condition, they could be offered the choice of staying in their current health plan or of transferring to a center that focuses on their specific needs.

The beauty of such an approach is that it would encourage competition among providers and health plans to improve care. It makes the market work the way we would like it to work; competing to offer improved care for a competitive price.

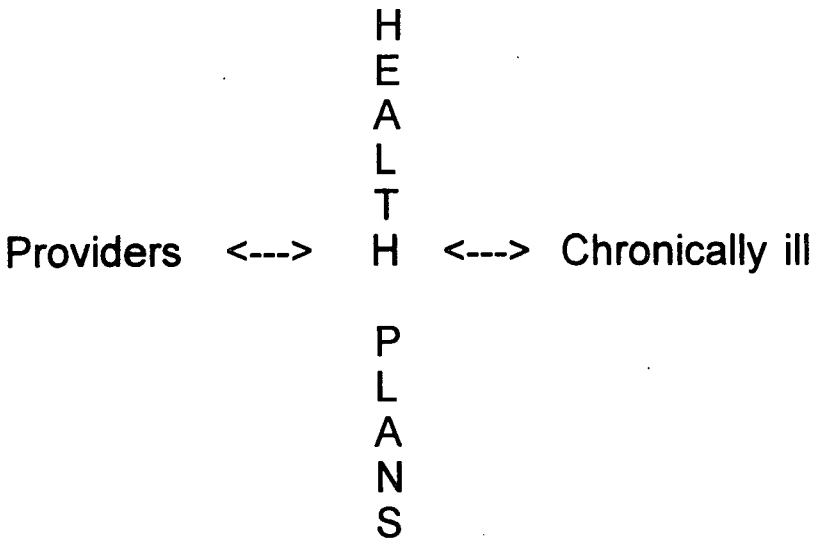
The amount paid out in these special programs could be subtracted from the basic funds used for Medicare - so it is a budget neutral approach. In fact, given the levels of inefficiency and waste in the fee-for-service system, especially when it comes to caring for this type of patient, it is very possible better managed care could not only provide better

quality but could bid prices below what Medicare is currently paying.

Mr. Chairman, the flaw in our competitive health plan market that diverts it from the chronically ill is a great tragedy. Alzheimers and other patients with complex chronic conditions are in many ways the ideal candidates for managed care, and for competition among health plans to provide it. We aren't going to save much money or make much medical progress in the short term by managing services to basically healthy people. We need the market to work to produce savings and improved care among the chronically ill. That is where the costs are - and it is where the greatest human need is.

I urge the committee to promote consideration by the Congress of reforms in how Medicare purchases care for these beneficiaries. It is going to take some new legislative authorities and some research to do it.

# DYSFUNCTIONAL MARKET



The CHAIRMAN. Mr. Steinke Healy.

**STATEMENT OF GRIFF STEINKE HEALY, CHAIRMAN,  
ALZHEIMER'S ASSOCIATION, WASHINGTON, DC**

Mr. HEALY. Thank you, Mr. Chairman. It's an honor to appear before you on behalf of the Alzheimer's Association. We in the Alzheimer's Association have always felt a very special partnership with this committee, on health and long-term care and medical research.

This hearing, as you know, could not be more timely. We are in the midst of major changes in our health care systems. We can view this as full of risk for our people or we can view it as an opportunity. We choose the latter. We choose to view it as an opportunity.

As you heard from the first panel, our health care system does not always work well for people with Alzheimer's disease. There are many reasons for this. Alzheimer's disease cannot be cured with a prescription or with surgery. Geriatric training remains rare. Reimbursement does not recognize the added costs of treating a patient with dementia and separate financing for acute and primary care on the one hand, and long-term care on the other, encourages the shifting of costs and accountability.

There is no place in the system currently that is responsible for the whole person. We all share some of the blame.

In our efforts to focus attention on long-term care, perhaps we have drawn too bright a line between medical care and custodial care. In our efforts to avoid over-medicalizing services, we may have lost track of the fact that continuing care is very much a piece of health care.

Much of what we tend to think of as long-term care for people with chronic illness is, in fact, preventive health care and health maintenance.

It's time for all of us to begin thinking in a new way. We can no longer accept the verdict that a doctor's diagnosis of Alzheimer's disease means that there is nothing that can be done. There is a lot that can be done to manage the disease, to maintain function, to prevent illness, and to prevent excess disabilities, such as those that you heard about in the earlier panel.

We need to acknowledge that adult day care is, in fact, treatment for Alzheimer's disease, just as dialysis is treatment for kidney disease and nutrition is part of treatment for diabetes.

We need to connect the dots on Alzheimer's care so that the doctor, the family, and the community care provider or the nursing home are part of the team that is coordinating care for the whole person.

That means changing the way that doctors and nurses think and act. I was delighted to hear the comments about physician education and tying them into the whole system of social responsibility and social treatment, as well as strict medical treatment.

It means changing the way aging service providers think and act, and it means changing our health care financing system over time.

The private sector needs to play a significant role in this.

On behalf of the Alzheimer's Association, I am pleased today to announce a major new initiative to make managed care work better



for people with Alzheimer's disease and related dementias. Hopefully this will get to the point that you made in talking with Mr. Jones regarding the problem of "strategic mediocrity."

We are undertaking a new initiative that has two components. As a first step, we are providing funds to three of our chapters—in Los Angeles; Columbus, OH; and in Philadelphia—to work with health maintenance organizations in their communities to develop models of high-quality dementia care. They will be working with three of the largest managed care companies in the country, including Kaiser Permanente, who is represented by Ms. Eddleman Robinson to my right; United Health Care; and Aetna U.S. Health Care.

Over time, we hope to collect cost and outcomes data that will help managed care companies, States, and the Health Care Financing Administration develop standards, quality assurance systems, and risk adjustments.

The second part of our managed care initiative involves the National Chronic Care Consortium. We will create the first national demonstration of integrated, acute, primary, and long-term care particularly designed to respond to the needs of persons with Alzheimer's disease.

The Association is providing the seed money to develop the demonstration, and we will be seeking major foundation support to implement and evaluate those projects.

Congress must also continue to play a critical role. We must, at some point, return to the issue of comprehensive health reform, and we must do that as soon as feasible. We have to find a way to spread the financial risk of Alzheimer's disease over the long term.

But before we get back to those larger questions, Congress can make significant improvements in health care delivery and financing. These are spelled out in our 1996 National Public Policy Program to Conquer Alzheimer's disease. I have a copy here, Senator Cohen, that I would like to present to you and have it be made part of the record, if I might do so.

◆ *Alzheimer's Association*

NATIONAL PUBLIC POLICY PROGRAM  
TO CONQUER ALZHEIMER'S DISEASE



## ABOUT THE ALZHEIMER'S ASSOCIATION



The Alzheimer's Association speaks for more than 4 million people who have Alzheimer's disease and related disorders and for the families who care for them. The Association is the only national voluntary health organization dedicated to Alzheimer research and support for those who are living with these devastating illnesses. The Association carries out its work through more than 200 local chapters, 2000 family support groups, and 35,000 volunteers.

Since it was founded in 1901, the Alzheimer's Association has committed over \$45 million in private funds to biomedical and health services research. We have led the effort to define quality care for people with Alzheimer's disease and to develop innovative approaches to long term care -- in respite, adult day care, community settings, and specialized programming in nursing homes and other residential care settings.

In 1996, the Association will continue its basic mission to support people with Alzheimer's disease and their families. We will also undertake several critical initiatives to advance knowledge about Alzheimer's disease and to improve the quality of Alzheimer care:

- ◆ The Alzheimer's Association's Ronald and Nancy Reagan Research Institute will concentrate private resources and voluntary contributions to accelerate the search for effective treatments for Alzheimer's disease.
- ◆ Our Managed Care Initiative will provide direction to managed care plans and providers through development of protocols, models and best practices.
- ◆ Our Centers for Excellence will develop state-of-the-art training for persons providing hands-on care for persons with Alzheimer's disease, beginning with nurses and nurse assistants.

The Association will continue to work nationally and in states and communities across the country to expand the shared commitment of the voluntary sector, industry, and government at every level to alleviate the tremendous toll that Alzheimer's disease and related disorders exact on our society.

### Cover:

*Frances Powers of Lebanon, PA, pictured here with her daughter Jessica and her husband Stephen, has early-onset Alzheimer's disease, like her mother and aunt before her. She worries about Jessica, her teen-age son Phillip, and her siblings, who are all living with the fear of Alzheimer's disease. Frances works with the Alzheimer's Association and has testified before the 104th Congress twice to raise awareness of the disease, the need for accelerated research and for support to families dealing with the disease. "I want people to see me now," says Frances, "and as my disease progresses. I don't want this to happen to others."*

## ALZHEIMER'S DISEASE - *The Public Health Crisis of the 21st Century*

The United States is facing a public health crisis that will devastate families, overwhelm the health care system, and bankrupt federal and state budgets in the 21st century. This crisis is Alzheimer's disease. It already afflicts 4 million people in this country – every one of whom eventually requires full time care. The annual cost of the disease now exceeds \$100 billion.

Families – spouses, adult children and grandchildren – bear most of that cost and provide most of the care. The disease forces them to give up their jobs, their savings for their children's education, their retirement security. Even with everything families do before they ask for help, people with Alzheimer's disease and related dementias fill half the nation's nursing home beds. As many as 75% of these residents may qualify for help from Medicaid, because they do not have enough money left to pay \$3000 to \$4000 a month on their own.

Alzheimer's disease and related dementias will become epidemic in the 21st century. By the time today's children approach retirement, Alzheimer's will claim 14 million people. The cost of caring for them is beyond calculation.

This crisis is looming for three reasons. The first is simple demographics. The fastest growing segment of our population is the age cohort most at risk of Alzheimer's disease. One in 10 of us who reach age 65 and nearly half of us who reach 85 will spend the last years of our lives with Alzheimer's disease. Alzheimer's disease, however, does not limit itself to the elderly. As many as 400,000 people in their 40s and 50s may have the disease as well.

Second, scientists have not discovered anything any one of us can do now – no change in diet or lifestyle or exercise – to reduce our personal risk of getting the disease. For many "baby boomers", the molecular mischief that causes Alzheimer's disease has probably already begun.

Third, our health care system is not prepared to deal with the onslaught of Alzheimer's. And, our current health care financing system provides almost no financial protection for individuals and families who face the high cost of the disease.

If we do not act now to bring Alzheimer's disease under control, we will leave our children with an unbearable physical, emotional and financial burden. Families are at the forefront of the battle against Alzheimer's disease and they are prepared to stay on the front lines. But they cannot do it alone.



## A CALL FOR ACTION

This 1996 National Public Policy Program to Conquer Alzheimer's Disease proposes a partnership between families, the Alzheimer's Association and government at every level. We call for action together on three fronts:

First and foremost, **RESEARCH** – to discover effective treatments to slow or halt the progress of the disease. This is the only realistic way to bring the disease and its attendant costs under control.

Second, **CHANGES IN HEALTH CARE** – to incorporate emerging strategies to manage and treat Alzheimer's disease and other dementias, prevent unnecessary health care expenditures, and deliver cost-effective quality care.

Third, **LONG TERM CARE FINANCING** – to provide basic protection for families faced with the overwhelming cost of care for a loved one with irreversible dementia, in ways that spread the financial risk as broadly as possible.

Some of our recommendations require modest investment of additional public funds. Many simply require that we spend existing resources better, in both the public and private sector.



## RESEARCH - *Creating a Future without Alzheimer's Disease*

Nothing in medical research is generating more excitement or optimism than the explosion of scientific discoveries about Alzheimer's disease. The potential for reducing human suffering and for saving health care costs is enormous.

The Congressionally-established Advisory Panel on Alzheimer's Disease indicates that delaying the onset or slowing the progress of Alzheimer's disease by as little as five years could cut in half the number of people with the disease. Millions of families would be spared the tragedy of Alzheimer's. And the annual cost of the disease could be reduced by more than \$50 billion. It is difficult to imagine a richer return on investment.

New discoveries about Alzheimer's disease suggest that even this goal may be too modest. In fact, it may be possible to delay Alzheimer's disease by as much as 20 years. This could effectively prevent the disease for the vast majority of persons at risk. At last, science has opened the door to the possibility of a future without Alzheimer's disease. But that door could be slammed shut if Congress cuts off the financial support scientists need to pursue these new avenues of research.

### *Genetic Discoveries Open Doors to Treatment and Potential Cost Savings*

Just two years ago, researchers funded by the National Institute on Aging found a gene (APOE) that appears to play a major role in the common form of Alzheimer's disease. The particular genotype a person inherits appears to change the onset of Alzheimer's disease by as much as 20 years. Now confirmed by researchers throughout the world, this is the first susceptibility gene for a major prevalent disease to be found through reverse genetics — a search that is underway in many diseases including diabetes, hypertension, and cancer.

As a risk factor, APOE does not predict whether or when any one individual will get Alzheimer's disease. But it can be an important adjunct to diagnosis of people who already present symptoms. With three other genes now identified in the uncommon form of inherited early onset Alzheimer's, these genetic discoveries hold the possibility of streamlining what is now a complex and expensive process of diagnosis. This would bring real health cost savings, particularly for Medicare.

Of even more importance and potential impact, these discoveries have allowed researchers to turn their attention to the basic mechanisms of the disease — to figure out what is causing brain cells to disconnect and to die. It is this type of research that will lead to development of compounds to change the way those mechanisms work — and to prevent the disease.

Two recent discoveries indicate the importance of this genetic information. Scientists are finding that certain drugs approved or being tested for treatment of Alzheimer's disease seem to affect people differently, depending upon their genotype. If these preliminary findings are confirmed, physicians will be able to target treatments to those for whom they are most likely to be successful.

## RESEARCH



Other scientists are now using brain imaging to detect and study changes occurring in the brains of people who, based on their genotype, would be expected to show signs of Alzheimer's disease 20 years from now on average. This will make a huge difference for testing treatments that correct abnormal metabolism when they are available – creating for the first time the potential for halting the progress of the disease before symptoms ever appear.

#### *New Treatments under Rapid Development*

Even while scientists are searching for more clues to the causes of and risk factors for Alzheimer's disease, new treatments are being tested around the country. Some, like estrogen and prednisone, are already available for other medical conditions; their potential use in Alzheimer's was identified by earlier studies of brain function and possible Alzheimer risk factors. Newly reported research on a genetically produced mouse model for Alzheimer's disease opens the door for more rapid screening of new compounds that may work on the underlying causes of the disease – allowing earlier and speedier testing than it is possible to do in humans.

At the same time, health services and behavioral research is finding new techniques for nondrug treatment of Alzheimer's disease through direct interventions with persons with the disease, training and supports for family caregivers, specialized care programs, and culturally and ethnically sensitive care practices. This research is being transferred rapidly to practice in health and long term care settings, with impact on patient outcomes and function.

#### *Future Progress Threatened by Budget Reductions*

For 15 years, Congress, the National Institutes of Health (NIH) and the Alzheimer's Association have steadily increased their commitment to research on Alzheimer's disease and related dementias. Together we have built an infrastructure that now includes more than 3000 scientists working on Alzheimer's and a solid body of knowledge about the disease. But now, federal budget decisions threaten to compromise the ability of scientists to apply the fruits of this research. At the central core of the Alzheimer research network, the Alzheimer's Disease Centers funded by the National Institute on Aging already absorbed a 9% budget reduction in 1995, forcing them to cut personnel and patient-based research at the most critical point. At today's funding levels, less than one in four approved investigator-initiated projects submitted to NIH was funded. If this continues, discoveries that are right around the corner, with potential to yield huge savings in health care costs by the turn of the century, will be put off and perhaps lost forever.

Recognizing the unprecedented opportunity in Alzheimer research today, the Alzheimer's Association is redoubling its commitment through the newly established Alzheimer's Association's Ronald and Nancy Reagan Research Institute. The Association calls on Congress to renew its commitment as well – maintaining funding for health research in general and for Alzheimer research in particular as a high national priority.

## RESEARCH RECOMMEN

- ◆ Congress should appropriate a minimum of \$350 million for Alzheimer research in 1997 for biomedical, behavioral and health services research. This is the absolute minimum needed to maintain current research efforts and to allow funding for the highest priority new investigations. Further, Congress should set a funding goal of \$500 million for research on Alzheimer's disease and related dementias and establish a timetable to reach that funding level as rapidly as possible.
- ◆ To help reach the \$500 million goal, Congress should create a health research fund to supplement appropriations to the National Institutes of Health, with a secure source of funds outside the appropriations process.
- ◆ The National Institute on Aging (NIA) should continue its current emphasis on Alzheimer research, including adequate support for the Alzheimer's Disease Centers (ADCs). NIA should establish mechanisms to coordinate the work of the ADCs with Alzheimer's Association chapters, to avoid duplication and maximize available public and private resources.
- ◆ The Food and Drug Administration should treat Alzheimer's disease as a life-threatening disease – maintaining a focus on the disease through its Office of Special Populations, encouraging development of Alzheimer treatments, expediting review of such treatments, and assuring expanded access to experimental drugs that are affordable and safe.
- ◆ Congress should provide adequate funding to the Department of Veterans Affairs to ensure its commitment to geriatric research (particularly clinical research), education, and training with special emphasis on Alzheimer care.
- ◆ The federal government should continue to provide support to sustain the essential role of academic health centers in patient care, professional training, and research.
- ◆ Congress should continue support for the Safe Return program to complete development of a nationwide system to protect memory-impaired persons who are at risk of wandering, and to train law enforcement and emergency personnel to deal with people with dementia.



## HEALTH CARE AND MANAGED CARE -

### *Breaking Down Barriers to Effective Treatment*

The current health care system does not work well for people with Alzheimer's disease. There are a number of reasons for this — the absence of traditional types of medical treatment for the disease, the inevitability of decline and the ultimate outcome of the disease, the lack of geriatric training of health care professionals, and the failure of reimbursement systems to recognize the added costs of treating a patient with dementia. Most people who have Alzheimer's disease are Medicare beneficiaries, but they have difficulty accessing Medicare benefits, including rehabilitation, hospice, and diagnostic tests because providers are not trained to deal with patients with dementia or because carriers refuse to pay.

People with Alzheimer's disease suffer from the arbitrary distinctions that have been drawn between health care and social services. When the diagnosis is Alzheimer's disease, physicians may say "there is nothing we can do", even though emerging alternative forms of therapeutic treatment like adult day care have a proven positive outcome on the patient's health and well-being. Counseling and respite services for family caregivers are considered outside the realm of health care, even though such services are shown to reduce stress and illness in the caregiver and to improve the functioning of the person with Alzheimer's disease.

We have also drawn too bright a line between acute and primary care on the one hand and long term care on the other. Whether or not the person with Alzheimer's disease has other acute and chronic ailments that confound their dementia and complicate their treatment (a common occurrence in older Alzheimer patients), there is little if any continuity or coordination between those who are meeting her/his basic health care needs and those who are providing day to day care.

Hospitalization of a person with Alzheimer's disease often precipitates a decline unconnected to the basic reason for the hospitalization. The transfer is traumatic in itself for a person who cannot comprehend what is happening. And the care practices used in the hospital, including use of physical and chemical restraints, are often in direct conflict with the practices used at home or in the nursing home. New research suggests that infections for which nursing home residents are routinely hospitalized can be treated effectively in the nursing home, with similar outcomes, at one-third of the cost, but practice and reimbursement policy still encourage hospitalization.

Family frustrations with the current health care system were confirmed in a recent poll conducted for the Alzheimer's Association which found that, while people confronted with Alzheimer's would turn first to their physician, they were skeptical about being able to get the type of help they needed, even things as basic as information about the disease and help in treating symptoms and handling day to day care.

# HEALTH CARE AND

Health care providers and insurers (including Medicare) must consider Alzheimer's disease a medical condition which they have a responsibility to treat and manage – even when that requires the use of services not typically considered medical, and that care is best provided outside the hospital or the doctor's office. Reimbursement systems – public and private – must reward providers for such behavior.

Given their experience with the health care system, Alzheimer families have reason for concern about managed care, particularly if pressures to restrain costs discourage basic services like full diagnosis, access to the most effective prescription drugs, or the use of specialists when appropriate. But managed care plans also have a unique opportunity to lead the way in the development of more appropriate and effective health care for people with Alzheimer's disease. The Alzheimer's Association has developed a focused initiative, working with the managed care industry to develop and promote models of effective care for persons with Alzheimer's disease. Recognizing, however, that Medicare will play an important role in these managed care developments, the Association recommends certain actions by government to support and enable these private sector initiatives.



# MANAGED CARE

## CARE RECOMMENDATIONS:

- ◆ The Health Care Financing Administration should clarify policies with regard to specific Medicare benefits, including rehabilitation services and diagnostic assessments, to assure that such benefits are available to beneficiaries with Alzheimer's disease. In addition, physician reimbursement policies should be modified to recognize the time it takes to treat a patient with cognitive impairment, including time for family counseling.
- ◆ The Health Care Financing Administration should develop appropriate capitation rates for Medicare managed care to account for the full costs of care for an enrollee with dementia.
- ◆ Medicare managed care plans should:
  - develop specific protocols for treatment of Alzheimer's disease and assure that all appropriate personnel are trained to provide such treatment;
  - provide full diagnostic assessment of persons displaying symptoms of Alzheimer's-type dementia, using interdisciplinary staff and specialists as needed;
  - assure access to appropriate prescription drugs for treatment, particularly of the behavioral symptoms associated with Alzheimer's disease;
  - provide essential treatment and disease management services for persons with Alzheimer's disease, including case management, therapeutic adult day care, and supportive services to family caregivers.
- ◆ The federal and state governments should promulgate regulations for managed care that assure open and equal access to plans, protect against discrimination including discrimination based on age and medical condition, provide sufficient information for individuals to evaluate health plans, protect against marketing abuses including specific protections for persons with Alzheimer's disease, and provide for quality assurance.
- ◆ Congress and the Health Care Financing Administration should support and encourage demonstrations that test innovative models of managed care for persons with chronic illness like Alzheimer's disease, including models that coordinate and integrate acute and long term care.
- ◆ Congress should continue the program of Alzheimer matching grants to the states under the Public Health Service Act to test methods to link family support services to primary health care providers. A minimum of \$5 million should be authorized and appropriated to fund such demonstrations.

## LONG TERM CARE FINANCING - *Protecting American Families*

The United States has failed to come to terms with the single largest uninsured health care problem in the United States – long term care. As a result, millions of families who thought they were well insured (through private health insurance, Medicare, and Medigap policies) are quickly bankrupted when a crisis like Alzheimer's disease strikes. And state budgets are being overwhelmed as those families are forced to turn to Medicaid as a last resort when there is nothing left to pay for care their loved ones need. The Congressional Budget Office estimates that more than 37% of the total Medicaid budget in 1996 will be spent on long term care.

Persons with Alzheimer's disease and related dementias represent the single largest group of long term care users. Over 4 million people in the United States have Alzheimer's disease today. Every one of them will require round-the-clock care anywhere from 3 to 20 years. More than half of the nearly 2 million residents of nursing homes today have Alzheimer's disease or another dementia. They have the longest and costliest stays, and as many as 75% eventually qualify for Medicaid to help with the nursing home bill – but only after they have exhausted their life savings paying for care.

Our current approach to long term care does not work for most people with chronic illness like Alzheimer's disease. It is based on a false assumption that most families can protect themselves against the high cost of long term care. In fact, most of the elderly do not have the money to pay for a nursing home that costs, on average, \$42,000 a year for a person with Alzheimer's disease. Median household income of the elderly is a little over \$17,160; median net assets of the elderly are \$56,000. Elderly women living alone (those most likely to end up in a nursing home) have assets of only \$12,700 – enough to pay for 3 to 4 months of care. Moreover, the typical elderly person is already spending 21% of his or her income on health care – not including long term care. And with annual household median income for all age groups at just \$34,000, relatively few adult children can contribute much to the cost of their parents' care.

For most of the elderly, separate private long term care insurance is not an answer. For a healthy person age 65, the cost of a good long term care insurance policy now can be \$1600 to \$2000 a year; this is on top of almost \$1300 the elderly now pay in premiums for Medicare and supplemental insurance for basic health care. Even the most optimistic estimates assume that no more than 40% of the elderly could afford even a modest long term care insurance policy. And no one, no matter how much money they have, can buy a policy if they have any symptoms to suggest they may have Alzheimer's disease.



Medicaid has become a long term care safety net by default. And that is now jeopardized by federal and state efforts to control spending. Alzheimer families are finding appropriate nursing home placements increasingly difficult, because facilities do not want to take a financial risk on people who are likely to spend down to Medicaid. At the same time, cuts imposed by Congress are likely to make it more difficult for states to maintain and expand the emerging home and community care programs which could offer cost-effective alternatives for care. In increasing numbers, elderly persons who have worked all of their lives will see their savings disappear, their spouses impoverished, and their adult children trapped in the middle, left with impossible choices between caring for their parents and providing for their own children.

The United States cannot meet the long term care needs of an aging population in the 21st century using current systems to finance and deliver long term care. Ultimately, we must find the way to provide long term care protection for everyone who needs it through a system of health insurance (based on public or private insurance or some combination thereof) that spreads the financial risk as broadly as possible. Recognizing that the country is not prepared to address this broader issue in 1996, the Association makes the following recommendations for smaller but significant improvements that will move us toward this goal.



## LONG TERM CARE RECOMMEND

- ◆ Expenses for long term care, including home and community care and residential care, should be fully deductible as medical expenses for state and federal income tax purposes.
- ◆ Congress should require uniform national standards and consumer protections for private long term care insurance, based on the work of the National Association of Insurance Commissioners.
- ◆ Until comprehensive long term care financing is in place, Medicaid should be retained as a federal-state program, with an individual guarantee of coverage under state plans, income eligibility rules that recognize high out-of-pocket medical expenses including long term care, protections against impoverishment for spouses of nursing home residents, and adequate funding to accommodate growth in the need for assistance.
- ◆ Any state or federal long term care policy or program, including Medicaid, should include the following to ensure equitable treatment of persons with dementia:

Eligibility definitions that give equal consideration to persons with cognitive impairment who need supervision or stand-by help (including reminding and cuing) with activities of daily living or supervision because of behavioral symptoms of the disease;

Appropriate use of home and community care, including personal care, companions, adult day care, respite, and alternative forms of residential care (including assisted living). Choice of settings and services should be based on an individual plan of care developed with the individual and the individual's family;

Use of sliding fee scales based on ability to pay, with protections for low income individuals and particular consideration of the needs of spouses and other dependents of the person receiving assistance;

- ◆ Federal nursing home quality standards must be maintained — including those related to the guarantee of services to each resident to attain or maintain the highest level of well being, individual resident assessment and care planning, protection against physical and chemical restraints, staffing, and staff training. The federal government and the states must assure full enforcement of the standards, in a manner that recognizes the specialized needs of residents with dementia.
- ◆ Congress should reauthorize the Older Americans Act and provide adequate funding for community services, including services for the frail elderly and caregiver support services under Title III of the Act, and for ombudsman programs under Titles III and VII.

## FACTS ABOUT ALZHEIMER'S DISEASE

The American people cannot wait any longer for answers to Alzheimer's disease. And families cannot wait any longer for help. The facts speak for themselves.

- ◆ Over 4 million people in the United States have Alzheimer's disease. By the middle of the next century, 14 million will have the disease.
- ◆ Alzheimer's disease is already the third most expensive disease in the United States, after heart disease and cancer. It now costs at least \$100 billion a year.
- ◆ One in 10 persons over 65 and nearly half of those over 85 have Alzheimer's disease. People in their 40s and 50s also get Alzheimer's disease.
- ◆ A person with Alzheimer's disease will live from 3 to 30 years after the symptoms appear. For much of that time, he or she will need full-time round-the-clock care.
- ◆ The average lifetime cost of Alzheimer's disease per person with the disease is \$174,000.
- ◆ More than 7 in 10 people with Alzheimer's disease live at home. While families provide almost 75% of their care, they also spend on average \$12,500 a year for paid help.
- ◆ At least half of nursing home residents have dementia. The average cost of Alzheimer care in a nursing home is \$42,000 a year.
- ◆ The federal government will spend an estimated \$324 million on Alzheimer research in 1996. That is \$1 for every \$309 the disease now costs the American people and \$81 for each person who has the disease.

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Yusaku Saitoh, PhD  
UCSD School of Medicine

Seungnam Seon, PhD  
Johns Hopkins University

John R. Sluiter, Jr., PhD  
The Neuroscience Institute  
University of Health Sciences/  
The Chicago Medical School

Dawn O. Smith, PhD  
University of Hawaii

Warren Strimling, MD  
Duke University Medical Center

Linda Teri, PhD  
University of Washington

Leon Thal, MD  
NIH Medical Center

John G. Trojanowski, MD, PhD  
University of Pennsylvania  
School of Medicine

Michael P. Vitek, PhD  
Duke University Medical Center

Bruce Wadsworth, MD, PhD  
Emory University





919 North Michigan Avenue  
Suite 1000  
Chicago, Illinois 60611-1676  
(312) 335-7700

*Edward F. Truschke  
President and CEO*

1319 I Street, N.W.  
Suite 710  
Washington, D.C. 20004  
(202) 898-7737

*Stephen McConnell, PhD  
Senior Vice President -  
Public Policy*

The CHAIRMAN. It will be included as part of the record.

Mr. HEALY. Thank you, sir.

Briefly, we make the following recommendations:

First, that Medicare should cover services like hospice, respite, and adult day care as cost-effective alternatives to hospitals, home health, and skilled nursing facilities.

The CHAIRMAN. Let me stop you there.

Mr. HEALY. Yes.

The CHAIRMAN. Do you have some empirical data that will show that it is cost-effective? One of the problems that I have had, the so-called "Kennedy-Kassebaum" bill, as you know, is on the floor and will be voted upon later this afternoon. I included in that a provision dealing with anti-fraud that I've been supporting for some years now.

Mr. HEALY. I applaud you for doing so. Thank you.

The CHAIRMAN. It's finally going to be included. But you know what? It has taken years for me to get CBO, the Congressional Budget Office, to "score" it. They have to say, "Yes, if you pass these changes in enforcing anti-fraud efforts, you will save \$3 billion over the next 6 or 7 years." Without that, there is great difficulty in getting it included. But now I can show actual savings, according to CBO. Can you do the same thing?

Mr. HEALY. If I might, Senator, if I could supplement the record in writing and ask my staff, we'll provide that information for you.

The CHAIRMAN. All right. That's fine. It will be helpful in persuading our colleagues that this is the right thing to do.

Mr. HEALY. Of course. I appreciate that.

[The information to be supplied follows:]

Mr. Chairman, you asked for data to demonstrate that Medicare coverage of services like hospice, respite, and adult day care could be cost-effective alternatives to hospitals, home health, and skilled nursing facilities. As I indicated in my statement to the committee, the Alzheimer's Association has launched an ambitious initiative with Medicare managed care plans and integrated chronic care providers which will provide important new data to help answer that question. However, we believe there is already compelling evidence to show the cost-effectiveness of these services, as well as improvement in the quality of life of the people who receive these services. For example:

- A 1993 study of the total cost of Alzheimer care found dramatic difference between the cost of care at home and in nursing facilities—not because total care needs were less but because if the person with Alzheimer's disease can stay at home with a reasonable amount of services, families can continue to provide most of the care they need. The cost of paid care in a nursing facility averaged \$42,049 a year, compared with \$12,572 for paid care for a person at home. Even among the most severely impaired, costs were dramatically different: \$16,278 at home and \$42,477 in a nursing facility.
- According to the Robert Wood Johnson Foundation, the average daily cost of adult day care is \$50, for as much as 8 hours of care. The average cost of a single home health visit can equal or exceed that amount.
- A 1993 study supported by the National Institute of Mental Health examined the impact of interventions with spouse-caregivers of people with Alzheimer's disease, including individual and family counseling, support group participation, and ad hoc consultation. Those persons whose caregivers received such services had less than half as many nursing home placements as persons whose caregivers did not receive such services. Yet Medicare does not reimburse for such services.
- A 1992 study of patients in a major metropolitan medical center found that patients with dementia suffered more frequently from life-threatening infections, sepsis, introgenic disease, and prolonged hospital stays, resulting in hospital losses 75 percent higher for demented patients than nondemented patients. The authors attributed this to a number of factors directly related to dementia, including problems with feeding, continence, and mobility, malnutrition, accidental injuries, poor

compliance with medication orders, nonrecognition or misinterpretation of signs and symptoms, and deficits in health-seeking behavior—all of these are realities of daily life of an Alzheimer patient that can be addressed directly through caregiver training, ongoing disease management by physicians and related personnel, and programs like adult day care with staff trained to monitor health status, oversee medication, and recognize early warning signs of comorbid health problems.

• In 1995, Lewin-VHI completed an analysis of the Medicare Hospice Benefit which showed that Medicare beneficiaries who enrolled in a hospice program cost Medicare \$2737 less, on average, than non-users of hospice. Part A expenditures were \$1787 lower; Part B expenditures were \$950 lower. Most of those savings accrued in the last month of life.

Mr. HEALY. Second, we recommend that Medicare reimbursement, including capitation rates for managed care, should be adjusted for the actual cost of providing quality care to persons with dementia.

Third, we recommend that Congress encourage further innovations to coordinate and integrate financing and delivery of the full continuum of care for people with chronic illnesses like Alzheimer's disease.

Fourth, Congress must maintain the long-term care safety net that families now have through Medicaid. We support flexibility for the States, particularly to encourage community-based care.

I must tell you, however, that we are absolutely opposed to replacing title XIX with a block grant. This moves in exactly the wrong direction. It would eliminate essential guarantees for exhausted families. It would further fragment financing and delivery. We should be trying to bring systems together and not tear them apart.

Congress must preserve—and I was delighted to hear you refer to this, and your efforts and those of Senator Pryor and your comments earlier—Congress must preserve Federal nursing home quality standards and the Federal role in overseeing State enforcement of these standards.

We appreciate the leadership that you have shown.

Congress should clarify that families' out-of-pocket long-term care expenses are deductible as medical expenses. Again, we're delighted about what's happening this afternoon.

We are pleased that the health insurance legislation includes tax clarification, and we urge you and your colleagues, when you go to conference, to please insist on the earlier effective date that is in your legislation. Congress should not put this off until 1998, as is proposed by the House of Representatives.

Finally, Congress must continue a reasonable level of investment in Alzheimer's research. You are entirely right about the long-term costs—and I am part of that baby boom generation that will triple or quadruple the number of Alzheimer's patients and victims in this country. The only way to control the long-term cost is through research.

We are asking this year for not less than \$350 million for fiscal year 1997 as the only realistic way to control the huge cost of this disease.

Senator I thank you very much for having us.

The CHAIRMAN. Thank you very much for your testimony.

[The prepared statement of Mr. Healy follows:]



TESTIMONY OF

GRIFF STEINKE HEALY  
CHAIRMAN OF THE BOARD  
ALZHEIMER'S ASSOCIATION

presented to

SPECIAL COMMITTEE ON AGING  
UNITED STATES SENATE

April 23, 1996

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

Washington Office: 1319 F St., NW, Suite 710 • Washington, DC 20004 • Phone: (202) 393-7737 • Fax: (202) 393-2109

TESTIMONY OF GRIFF STEINKE  
CHAIRMAN OF THE BOARD  
ALZHEIMER'S ASSOCIATION

April 23, 1996

Chairman Cohen, Senator Pryor and Members of the Committee. It is an honor to appear before you on behalf of the Alzheimer's Association. We are the national voluntary health organization that speaks for the 4 million Americans who have Alzheimer's disease and the 20 million family members who care for them. We have always felt a special partnership with this Committee as we work to improve the health and long term care system, to support families, and to find answers to this awful disease.

We are in the midst of major upheaval in our health care systems. Much of this is happening in the private marketplace. But it will be heavily influenced by the decisions Congress makes with regard to Medicare and Medicaid -- principal sources of health and long term care financing for people with Alzheimer's disease. There are two ways to look at all of this change. We can see it as full of risk for our people -- which indeed it may be. Or we can view it as opportunity. We prefer to focus on the opportunity.

The fact is: our health care system does not work very well now for people with Alzheimer's disease. There are many reasons for this. Doctors cannot "fix" Alzheimer's with a prescription or a surgical procedure. Geriatric training is still rare. Reimbursement systems do not recognize the added costs of treating a patient with dementia. And separate financing for acute and primary care on the one hand and long term care on the other encourage shifting of cost and accountability. There is no place in the system that is responsible for the whole person.

We can all share some of the blame for this state of affairs. In our efforts to focus attention on the needs of people with Alzheimer's disease and the importance of long term care in general, perhaps we have drawn too bright a line between medical care and what some (inappropriately) call "custodial care". In our efforts to avoid "overmedicalizing" services, we have perhaps lost track of the fact that long term care is just as much a part of health care as is acute and primary care. Much of what we call long term care for people with chronic illness is in fact preventive health care and health maintenance.

It is time to think in a new way. We can no longer accept a doctor's verdict that, once the diagnosis is Alzheimer's disease, "there is nothing we can do." There is much we can do, to manage the disease, to maintain a person's remaining functional abilities, and to prevent illness and excess disabilities.

We need to acknowledge that a service like adult day care is treatment for Alzheimer's disease, just as dialysis is treatment for kidney disease, and nutrition education is part of treatment for diabetes.

And we need to "connect the dots" in the Alzheimer care system, so that the primary health care provider, the family caregiver, and the community care provider or the nursing home are part of a team that is coordinating care for the whole person. That means changing the way doctors and nurses think and act, it means changing the way aging service providers think and act, and it means changing our health care financing systems over time.

### The Private Sector Must Take the Lead

The Alzheimer's Association is announcing today a major new initiative to make managed care work for people with Alzheimer's disease and related dementias. This initiative has two components. As a first step, we are providing funds to three of our Chapters to work with Health Maintenance Organizations in their communities to develop models of high-quality dementia care. These HMOs are among the largest managed care companies in the nation.

- Our Los Angeles Chapter is working with Kaiser Permanente of Southern California.
- Our Central Ohio Chapter in Columbus is working with United Healthcare.
- Our Greater Philadelphia Chapter is working with Aetna/U.S. Healthcare.

We do not start with a preconceived notion of a single best way to manage health care for people with dementia. The test sites will try different approaches, including case management, professional training, respite and caregiver support, and development of treatment protocols. As these models go forward, they will feed information back to us about problems and opportunities. Over time, we hope to collect cost and outcomes data that will help managed care companies, states, and the Health Care Financing Administration to develop the standards, quality assurance systems, and risk adjustments needed to assure quality Alzheimer care.

The second part of our managed care initiative involves the National Chronic Care Consortium. Together, we will create a national demonstration of integrated acute, primary, and long term care with managed care financing. The Consortium includes 27 member organizations, each an independent health care system working to develop ideas and technologies to provide integrated care for people with chronic illnesses. This demonstration will mark the first attempt to develop systems that respond particularly to the needs of persons with Alzheimer's disease. The Association has provided initial funding to develop the demonstration. We will be seeking major foundation support to implement and evaluate the projects.

### Congress Will Play a Critical Role

The health care policy decisions Congress makes, particularly on Medicare and Medicaid, have an enormous influence on Alzheimer care. Because Alzheimer's disease is so closely associated with advancing age, most people with the disease -- and their caregivers -- receive their health insurance through Medicare. And because Alzheimer care is so expensive and goes on for so many years, a very substantial proportion of persons with the disease will eventually spend down to Medicaid for help paying for long term care.

Ultimately, we as a nation must return to the issue of comprehensive health reform, to find a way to spread the risk of a long term illness like Alzheimer's disease as widely as possible. But even in this immediate period of lowered expectations and intense budget pressures, Congress can make incremental but significant improvements in health care delivery and financing. These are spelled out in the Alzheimer's Association's 1996 National Public Policy Program to Conquer Alzheimer's Disease. I have a copy of the Program here which I would like to submit for the record.

Very briefly, we make the following recommendations:

- 1) Medicare policy should recognize that services like hospice, respite, adult day care, and non-face-to-face consultation between physicians, families, and community care providers are cost-effective alternatives to the hospital, home health, and skilled nursing benefits which Medicare now covers.
- 2) Medicare reimbursement, including capitation rates for managed care, should take into account the actual costs of providing good care to persons with cognitive impairment.
- 3) Congress should encourage further innovations to coordinate and integrate care for the frail elderly and people with chronic illnesses like Alzheimer's, and should consider giving provider status to integrated systems that have demonstrated their effectiveness.
- 4) Congress must maintain the protections families now have under Medicaid for long term care assistance. The Alzheimer's Association supports and encourages additional flexibility for states, particularly to encourage long term care options in the community. But we are absolutely opposed to replacing Title 19 with a block grant. This moves us in exactly the wrong direction. In addition to eliminating essential guarantees for exhausted families, it will result in even further fragmentation of financing and delivery. We should be moving to bring these systems together, not tear them totally apart.
- 5) It is also essential that Congress preserve the federal nursing home quality standards that are beginning to make a major difference in quality care, and that the federal government maintain its role in overseeing state enforcement of these standards. We appreciate the leadership that you, Senators Cohen and Pryor, have provided on this issue.

- 6) Congress can give families some financial help now, by clarifying the tax code with regard to out-of-pocket long term care expenses. We are pleased that health insurance legislation which the House and Senate have now passed includes this tax clarification, although we are disappointed that the effective date would be postponed until 1988.

If Congress is going to extend these tax considerations to private long term care insurance as well, then it is essential that you require strong uniform consumer protection standards for these policies. At a minimum, you should require that current standards adopted by the National Association of Insurance Commissioners in its model Act and Regulations apply.

- 7) Finally, Congress must continue a reasonable level of investment in Alzheimer research. This is the only realistic way to control the huge cost of this disease, which has already reached \$100 billion a year and will explode in the 21st century as the numbers of people with Alzheimer's more than triples. If scientists can find a way to delay the onset of Alzheimer's by as little as 5 years, we have a chance to cut the incidence of the disease and reduce its costs by half. That goal is now well within reach.

At a steadily increasing pace, scientists are announcing major breakthroughs in Alzheimer research -- in genetics, understanding disease mechanisms, and potential treatments. This is the direct result of the significant increases in Alzheimer research funding Congress approved in the early 1990's. That level of investment has flattened in the past several years, however, and is now beginning to erode, just as the clear paths to major discoveries have been opened. The Alzheimer's Association encourages Congress to approve a modest increase in Alzheimer research funding, from an estimated \$324 million in 1996 to \$350 million in 1997. This is barely enough to keep pace with inflation and assure that the highest priority research projects are funded.

The Alzheimer's Association continues to recognize its responsibility to encourage cutting edge Alzheimer research. We remain the single largest funder of such research, outside the National Institutes of Health. Since our founding, we have committed over \$45 million to biomedical and health services research. Now, through the Ronald and Nancy Reagan Institute, we are intensifying that research effort. Neither NIH nor the Association can afford to let up on this essential commitment at this critical time.

Again, thank you for holding this important hearing today and for inviting the Alzheimer's Association to participate. I will be happy to answer your questions.



The CHAIRMAN. Ms. Eddleman Robinson.

**STATEMENT OF EDITH EDDLEMAN ROBINSON, LCSW, DIRECTOR OF SOCIAL MEDICINE, KAISER PERMANENTE MEDICAL CARE PROGRAM, LOS ANGELES, CA**

Ms. ROBINSON. Mr. Chairman, thank you for the opportunity to appear here today. I am a board-certified clinical social worker, and also administrator of social works services at Kaiser Permanente's Los Angeles Medical Center.

Kaiser Permanente is the Nation's largest private nonprofit provider of health care services. We are in a unique position to recognize and experience the challenges of aging, since we are greater than 50 years old and many of our long-term members are now confronted with dementia and other issues of aging.

Since 1984, 500 volunteers and a small staff of the Los Angeles chapter of the Alzheimer's Association have provided services to over 55,000 patients and families. These dedicated people are carrying out the National Association's mission of assisting Alzheimer's victims and caregivers, educating the public and health care professionals, supporting research, and advocating improved public policy.

Both Kaiser Permanente and the Alzheimer's Association recognize that there are three major categories of concern in the management of persons with dementia: diagnostic accuracy, post-diagnostic treatment, and assuring continuity of care.

Approximately 8 months ago, the two organizations formed an alliance to assure well-integrated, high-quality services to Kaiser Permanente members who are experiencing dementia.

The alliance convened a work group consisting of staff and volunteers from the Alzheimer's Association and staff and physicians from Kaiser Permanente. Our representation is multidisciplinary. Four work groups were established. Each work group includes both Kaiser Permanente and Alzheimer's Association representatives.

The diagnostic work group was established to assess how Kaiser Permanente members with probable dementia are currently evaluated, and also to facilitate the development of diagnostic protocols.

The systems of care work group was charged with developing a care model and pathway outlining how people with probable dementia and their families will receive care and support over the course of the disease.

The education work group's mission is to develop training programs for physicians and other providers of health care in the Kaiser Permanente system and to organize educational opportunities for our patients and their families.

The evaluation work group's mission is to design a tool that assures continuous enhancement of service and measures the progress of the program.

To date, we've achieved some of the following tasks:

Kaiser Permanente is developing regional practice guidelines for the diagnosis of Alzheimer's disease. These will be shared nationally as a best practice. We expect these guidelines to be completed this summer.

Second, a physician educational program is being developed to familiarize the Kaiser Permanente staff and physicians with the

guidelines. A questionnaire has been developed and distributed to all Kaiser Permanente practitioners in Los Angeles to define a baseline of the practice patterns of the providers.

Finally, we have had numerous joint educational endeavors. The Los Angeles executive director of the Alzheimer's Association, for example, spoke on providing continuity of care to Alzheimer's patients at Kaiser Permanente's national social worker recognition luncheon in March.

The group has developed a proposal with time lines set primarily for 1996 and very early 1997. One is that we will establish a system of care with case management as its cornerstone. We are proposing two case manager specialists in dementia, one at each of the two medical centers in our Los Angeles member service area. The Alzheimer's Association will provide the training.

A key component of the case managers' responsibility will include interdisciplinary team education.

Because it is often difficult for the providers to identify signs of early dementia in patients, it is critical for those close to the patients to call the patients deteriorating cognitive status to the attention of the patient's providers. The case managers will assist in identifying these patients. They will provide patient care planning to assure continuity of care, and they will lead support groups affiliated with the Alzheimer's Association. Also, they will be able to access funds for respite care.

We are proposing a coordinated and planned educational program on dementia and dementia care issues that will be developed for Kaiser Permanente personnel at all levels. Some of the training will be incorporated into ongoing in-service training programs. The Alzheimer's Association will develop the training programs with Kaiser Permanente education and training department staff.

We also will develop a third evaluation component to demonstrate the effectiveness and/or opportunities for improvement.

Both of our organizations are very excited about the continued success of this project and our alliance. We look forward to achieving similar positive results to those that we've already experienced, and I personally have both a professional and a personal interest in this topic.

I thank you for your time.

The CHAIRMAN. Thank you very much for your testimony.

[The prepared statement of Ms. Robinson follows:]

**The Kaiser Permanente/Alzheimer's Association Alliance**  
**An Integrated System of Care for**  
**Alzheimer's Disease and Related Disorders**

*Testimony of Edith Eddleman-Robinson, L.C.S.W.*  
*Kaiser Permanente Medical Care Program, Southern California Region*  
*April 23, 1996*

Mr. Chairman and Committee Members:

Thank you for the opportunity to testify here today on this very important subject. I am Edith Eddleman-Robinson. I am a board certified clinical social worker. I am also the Administrator of the Social Medicine Department at the Los Angeles Medical Center of Kaiser Permanente's Southern California Region.

Approximately four million (4,000,000) Americans suffer from Alzheimer's Disease or related disorders. Although dementing conditions can afflict any age group, they are more common in later life. These diagnoses affect approximately 10 percent of the population over age 65 and as much as 47 percent of those over age 84 (Evans, et al., 1989). Alzheimer's Disease is the fourth leading cause of death in the United States (Alzheimer's Association, 1995). With the aging of the baby boomers, the numbers are projected to increase to 14 million by the middle of the next century (Alzheimer's Association, 1995).

Kaiser Permanente and the Alzheimer's Association have formed an alliance committed to enhancing the care of individuals and families affected by Alzheimer's Disease. This relationship provides a unique opportunity to design a system of care that will ensure that our members receive the highest quality of care and quality of service possible when confronted with this catastrophic diagnosis.

***Kaiser Permanente***

The Kaiser Permanente Medical Care Program is a predominantly prepaid, group practice health maintenance organization that is committed to providing excellence in both quality of care and quality of service. The Program in Southern California consists of three closely cooperating organizations: Kaiser Foundation Health Plan, Inc., a California nonprofit corporation that is a federally qualified HMO; Kaiser Foundation Hospitals, a California public benefit corporation; and the Southern California Permanente Medical Group, a multispecialty physician group practice organized as a partnership. Nationwide, Kaiser Permanente is the largest private, non-profit provider of health care services in the United States, with over 6.8 million members in 16 states and the District of Columbia.

Kaiser Permanente was first offered to the public over 50 years ago. As a result, we are in a unique position to recognize and experience the challenges of aging. Many of our long term members are now confronted with dementia and other issues of aging. In Metropolitan Los Angeles alone, we serve a multi-cultural, socio-economically diverse population which includes over 40,000 Kaiser members who are age 65 and over. Additionally, Kaiser Permanente offers Senior Advantage, a product that is specifically designed for the Medicare population. We are,

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therefore, particularly sensitive and eager to enhance the care to our members afflicted with Alzheimer's Disease.

The Los Angeles Member Service Area of Kaiser Permanente consists of two hospitals and numerous medical office buildings within the Metropolitan Los Angeles Area. One hospital is located in the West Los Angeles area and the other is located on Sunset Boulevard in Hollywood. The Sunset Boulevard facility is the tertiary Medical Center for the Southern California Region. It is also a teaching facility and is affiliated with both the University of Southern California and The University of California at Los Angeles.

Kaiser Permanente's Metropolitan Los Angeles Member Service Area provides well organized continuing care services which include a Geriatric Program with an approved Geriatric Fellowship, extensive Social Work Services, a Geriatric Assessment Clinic, a Home Health Agency, a Hospice Program, Comprehensive Health Education Services, Utilization Management, and a Long Term Care Program.

#### ***The Alzheimer's Association***

The Alzheimer's Association is the National Volunteer Health Agency dedicated to researching the prevention, cure and treatment of Alzheimer's disease and related disorders and to providing support and assistance to afflicted patients and their families. In Los Angeles County, the Association's mission is carried out by: offering patient and family services to aid Alzheimer's victims and caregivers; educating the public and disseminating information to health care professionals; supporting research into the cause, prevention, treatment and cure for Alzheimer's disease and related disorders; advocating improved public policy; and promoting legislation.

The Los Angeles Alzheimer's Association was founded in 1982 by concerned family caregivers to make the future brighter for victims of dementia and their families. The Association's founders believed that by working together they could make a difference. The Los Angeles Alzheimer's Association was incorporated as a non-profit in 1984. Since then, through the efforts of over 500 dedicated volunteers and a small staff to support them, the Los Angeles Chapter of the Alzheimer's Association has provided services to over 55,000 patients and families.

#### ***Kaiser Permanente and the Alzheimer's Association – Working Together***

Kaiser Permanente's commitment to provide quality health care and service to the elderly and the Alzheimer's Association's mission are uniquely well-suited to each other. We view an alliance between the two organizations as in the best interest of improving health care delivery to a population affected by a very catastrophic illness. The alliance is an ideal method to identify and help to organize care for this segment of Kaiser Permanente's large 65 and over membership. Our partnership will help to assure well-integrated, high quality service to our members who are experiencing dementia.

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Both Kaiser Permanente and the Alzheimer's Association recognize that there are three major categories of concern in the management of persons with dementia: (1) diagnostic accuracy, (2) post-diagnostic treatment and (3) assuring continuity of care. Beginning in 1994, staff from the Los Angeles Chapter of the Alzheimer's Association and administrators and physicians from Kaiser Permanente's Southern California Region began discussions about mutual goals relating to patients and families confronting Alzheimer's Disease and related disorders. Approximately 8 months ago the two organizations formed an alliance to enhance the services provided to Kaiser Permanente members who are experiencing dementia. The agreed upon goal is to assure well-integrated, high quality health care and social services to this patient population.

The alliance convened a work group consisting of staff and volunteers from the Alzheimer's Association and staff and physicians from Kaiser Permanente. Kaiser Permanente's representation is multi-disciplinary, consisting of members of the Primary Care, Gerontology, Psychiatry, Neurology, Social Work, Health Education, and Pharmacy Departments, and Regional Administrative and support staff. As a result of this initial workgroup, the Alzheimer's Association developed a document that outlined some of the problems and possible solutions to serving people with dementia in health maintenance organizations. Using this document as a base, several additional work groups were established.

The *Diagnostic Work Group* was established to assess how Kaiser Permanente members with probable dementia are currently evaluated and to facilitate the development of diagnostic protocols. This group consists of representatives from the Primary Care, Neurology, Psychiatry Departments in Kaiser Permanente and the Alzheimer's Association.

The *System of Care Work Group* was charged with developing a care model and pathway outlining how people with probable dementia and their families will receive care and support over the course of the disease, beginning with evaluation and continuing through the final stages. This committee consists of representatives from Kaiser Permanente's Social Work, Psychiatry, Primary Care (both physician and Geriatric Nurse Practitioner), and Pharmacy Departments, and the Alzheimer's Association, both staff and volunteer.

The *Education Work Group's* mission is to develop training programs for physicians and other providers of health care in the Kaiser Permanente system and to organize educational opportunities for patients and their families. This group consists of representatives from the Health Education Department at Kaiser Permanente and the Alzheimer's Association.

The *Evaluation Work Group's* mission is to design a tool that assures continuous enhancement of service and measures the progress of the program.

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### ***Results to Date***

The collaboration has accomplished the following tasks to date:

A. Kaiser Permanente is in the process of developing regional practice guidelines for the diagnosis of Alzheimer's Disease, which will be shared nationally as a "best practice." This will ensure consistent use of the practices in the work-ups for dementia patients. We expect the guidelines to be completed by this summer.

B. A physician education program will be developed and utilized to familiarize the Kaiser staff and Permanente physicians with the guidelines.

C. A questionnaire has been developed and distributed to all Kaiser Permanente practitioners in the Metropolitan Los Angeles Member Service Area. Entitled the "Providers' Dementia Knowledge and Practice Survey," the questionnaire's intent is to define a baseline of the practice patterns of the providers. This includes identifying referrals and consultations used in the diagnostic phase, adjunctive resources used during the post-diagnostic phase, use of home health and social work services, knowledge of existing resources within Kaiser Permanente, knowledge of existing community based-resources, and an assessment of their perceived needs and desires for support. So far, there has been a solid response to the questionnaire -- approximately 20-25%.

D. Joint educational endeavors have occurred. The Alzheimer's Association participated in five Kaiser Permanente Senior Health Fairs during October, 1995, and will participate in two additional Senior Fairs during May, 1996 -- Older American's Month. The Alzheimer's Association participated in an educational event hosted by Kaiser Permanente, "Know the Facts About Memory Loss." The Executive Director of the Alzheimer's Association was the keynote speaker at Kaiser Permanente's annual National Social Work Month Recognition Luncheon. His topic was the Provision of Continuity of Care to Alzheimer's patients and their families.

### ***Planning to Move Forward***

The Group has developed the following proposal with time lines, primarily for 1996 and early 1997.

A. Establishment of a system of care with case management as its cornerstone. There will be two case managers, one placed at each of the two Medical Facilities that comprise the Metropolitan Los Angeles Member Service Area. The Alzheimer's Association will provide the training. These case managers will be specialists in dementia. A key component of the case manager's responsibility will include both informal and formal interdisciplinary team education regarding dementia.

Because it is often difficult for health care providers to identify signs of early dementia in patients, it is critical for those who are very close to the patient to call the patient's deteriorating

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cognitive status to the attention of the patient's health providers. Without this communication between providers and those who are close to the patient, impairment may not be identified and evaluated during the early and possibly even the middle stages of the illness. This means that many people with mild and possibly reversible impairment will not receive needed treatment. By facilitating communication and early treatment of dementia, the case managers will assist staff in identifying these patients and will provide care planning for these patients and their families. They will assure continuity of care for these patients as they move along the continuum of care, enabling them to access services both within Kaiser Permanente and the community at large. Each case manager will lead a caregiver class/support group which will be affiliated with the Alzheimer's Association. The case manager will be able to access funds for respite care.

B. A coordinated and planned educational program on dementia and dementia care issues will be developed for Kaiser Permanente personnel at all levels. Some of this training will be incorporated into ongoing in-service training programs. Some will be unique. The Alzheimer's Association will develop the training programs with Kaiser Permanente Education and Training Department staff.

C. A thorough evaluation component to demonstrate effectiveness and/or opportunities for improvement.

Both organizations are excited about the continued success of this project. We look forward to achieving similar positive results to those we have already experienced.

Identifying and providing continuous continuity of care to this patient population is critical to appropriate quality medical care. This is the core mission of both Kaiser Permanente and the Alzheimer's Association, and is at the heart of our alliance.

Thank you for your time. I would be happy to answer any questions you may have about the Alliance.

The CHAIRMAN. Dr. Phillips-Harris.

**STATEMENT OF DR. CHERYL PHILLIPS-HARRIS, M.D., CLINICAL RESOURCE DIRECTOR, CONTINUING CARE DIVISION, SUTTER/CHS, SACRAMENTO, CA**

Dr. PHILLIPS-HARRIS. I am truly delighted to be here. I am representing both Sutter/CHS, which is a large, integrated delivery system, the term of the 1990's, as well as the National Chronic Care Consortium, of which I am a board member.

My purpose for being here is to talk about what integrated care does look like, doesn't look like, and should look like, from both a provider's perspective, of which I fit in, as well as what it's like for the patients, the patients' families, and what isn't working, what are some alternatives.

My role within Sutter is as a geriatrician. I am a primary care physician for frail elders, as well as a certified medical director for several of our nursing facilities, an Alzheimer's special care facility, as well as one of the PACE replication sites, one of the demonstration projects that has been referred to.

The problem, I think, with the term "integrated delivery system" is that it has often meant fiscal relationships or ownership, and sometimes common signage and logos, and has very little to do with the impact of care for that family member, the children of that 88-year-old Alzheimer's patient that are trying to access systems within this conglomerate of delivery systems, unless the concept of integrated care really, truly means integrated care, not integrated fiscal relationships.

Going back to the maze that we've made reference to, the absurdity about this maze is that each one of these programs on that chart has different policy assumptions, different program authority, different eligibility criteria, different reimbursement formulas, but may be treating all the same patient. When you have families and case planners, discharge coordinators, even payers trying to figure out that morass, that is but the initial barrier to this whole concept of what we call integrated care.

Perhaps the most typical example of this fragmentation which leads to cost, redundancy, and lack of access, is in our duly eligible patients—those with Medicare and MediCal. Because the entire system is driven by facility payment, you have payment structures for one box that don't fit in another box, and therefore our care is reactive, it is crisis-driven, it's events-driven, and it's episodic.

A classic example is going back to the family with the 88-year-old mother with Alzheimer's. They may have mentioned to their family doctor multiple times that Mom was falling in her apartment, a common scenario. We realize that dementia is more than a memory loss, but also a special impairment.

The family physician says, "Well, I'm not really sure what to do about that. We have no resources for screening. We have no mechanisms for prevention."

But, sure shooting, when she does fall and break her hip we have this plethora of wonderful systems that immediately now come into place because we now have diagnostic codes for which to bill.

Then we get rather smug and we're proud that we have shut down the length of stay on a hip fracture from 6 days to 3 days,



feeling like that's successful, when we missed the boat in the first place.

So in this woman's process she now goes through the emergency room and to the acute care facility, has her surgery, is there for 3 days—or in California for maybe 3 hours—and gets out to a skilled nursing facility for rehab.

Unfortunately, because of her cognitive deficits, she doesn't do well in rehab, and therefore her Medicare part A benefits are denied and she goes to Medicaid, custodial long-term care, much like the tragic scenario that we heard about the woman's mother in earlier testimony.

Following this woman now along a little bit further—and it's not really—I will speak that there are quality issues profound throughout our system, but some of those quality issues relate to why we do what we do and how we get paid for what we do.

So this now frail, immobile demented woman who is not eating well develops a urinary tract infection, is dehydrated. Although the nursing home could intervene with these problems, there is no financial incentive to do so, so she's shipped back to the acute care facility for 3 days of IV antibiotics, a qualifying Medicare stay, and a feeding tube is placed.

Interestingly enough, when she goes back to the nursing home she now qualifies for a full 100-day Medicare part A benefits, so there is no incentive until about day 101 to even approach discontinuing the feeding tube.

You now have a totally immobile, demented, often permanently functionally impaired person, who the whole event triggered because of a hip fracture, and we have this vast array of costs in place that are generated by that one event, and yet nobody had the mechanisms to look at screening and preventing the fall in the first place.

Chronic disease, as we've heard throughout this morning, is not a benign issue. It's now representing 80 percent of all deaths and 90 percent of morbidity in this country. Alzheimer's disease and related dementias is now the fourth leading cause of death in patients over 65. We don't think about Alzheimer's disease, one, often as a medical disease—it is a mental problem; or, two, that it has a real significant morbidity and mortality impact on this population.

We've also heard over and over again that the social problems of chronic disease—there is no payment mechanism, providers didn't know what to do about it. There were no resources. So social problems became caregiver problems, and they quickly translated to medical crises, for which then we had billing codes to jump in and pretend to manage.

This conflicting cycle then causes patients to bounce back and forth, and when you asked the question about whether caregiver resources would provide care at less cost than traditional care, part of the problem is we don't know what we're spending on care anyway. HCFA hasn't been able to track the total cost of care for any chronic condition across payers, across providers, across funding sources, and so we have this kind of guess, although we know from what we're doing, just in the example of the 88-year-old with a hip fracture, is incredibly costly, incredibly redundant.

There have been some demonstration models that I know you're familiar with—the social HMO's, the PACE program—the Program of All-inclusive Care of the Elderly—which have been wonderful small demonstrations. The problem is that they apply to a very small group of people, when you look at the overall impact of chronic disease in our country.

The demonstration process is lengthy in its installation and in its application to a small number of providers, and both of these programs also have their own incentives.

The SMO's have limited long-term care, but as soon as you're in a nursing home their incentive is to move out. The PACE program, that I'm a strong advocate of, requires that people have to be frail before they even get there, and there is not a concept of disability prevention. What resources are we putting into looking at chronic illness and preventing these disabilities and functional decline before we're paying the costly services of acute care?

Managed care—we've heard what some of those dilemmas are.

First of all, I think many managed care organizations don't even have the understanding or resources of chronic disease. They certainly don't want to—they fail to market to this population.

I've used the example at Sutter, the "Field of Dreams" syndrome. "Build it and they will come." The last thing that an organization wants is to have the best chronic illness program because, indeed, that's what you get. That's what we talked about earlier. The speaker earlier mentioned about that whole concern of adverse selection.

Then, getting back to some of our reimbursement mechanisms, under the TEFRA Models, when you have the AAPCC—the average adjusted per capita cost—varying sometimes as much as four-fold within counties of States, the incentive is not for those counties that have very low rates to want to take risk. They'd just as soon put all the frail elders on a bus and move them to an area with a higher AAPCC, although clearly not feasible.

What health care providers need to put together for truly integrated care from the concept of the patient and the family is, first of all, we need access to all services. We can't piece meal in regions, and we might have some of this and a little bit of that. Access to all services includes caregiver resources, adult day health, respite, hospice, long-term care, in-home supportive services, meals, as well as the continuum of acute care and specialty services.

We need methodologies that identify risk for this population. One of the problems of managed care organizations is that they take a pool of enrollees and then they have no clue who it is that they're trying to serve, until the crises happen, we meet them in the ER, and then we try to deal with it by a shorter length of stay.

We need care coordination that's not just discharge planning that goes beyond facility movement of getting out of my box into your box, but actually coordinates care across this whole episode of the continuum.

We need flexibility of service that isn't defined by one facility, that long-term care is no longer defined as an institutional label, that you don't get the institutional risk adjusted rate just because you happen to be physically in a nursing home when those services may be provided on a community basis.

We need linked information systems. HCFA isn't the only one that has no clue what's going on. We, as providers, don't know what we're doing with patients from one day to the next.

We need shared financial incentives that truly reflect pooled shared risk and flexibility of dollars that measures the outcome of care, not the reimbursement structure. That's perhaps our biggest problem with fee-for-service—there is no mechanism to say better care is better. In fact, in many organizations worse care is better because it just generates more fee for service.

Recommendations: one is to move beyond the present demonstration project. I know that you've been a strong advocate of this.

Where we're limited right now is demonstrations require a few—very few—programs to be frozen in time to serve a very small number of participants, usually taking years before the program is actually even up and running, and that makes it relatively irrelevant for looking at dramatic changes in our delivery system in a short period of time. We don't have the luxury of years.

Second is to get legislative authority to grant waivers to more organizations who put together creative models of integrated care—again, tying into the present barriers with the demonstration process—to modify the current TEFRA payment policy that actually looks at risk adjustment, not at facility labels of risk adjustment, but on criteria.

The Chronic Care Consortium in 1995 submitted the Chronic Care Act, which defined a chronic care network as that providing a simple consolidated provider category under a single set of administrative requirements, payment policies, and reporting, and that these provider groups would be required to demonstrate their ability to integrate a full range of preventive primary, acute, and long-term care services.

This is one of the ideas of a creative intervention: to allow providers who have the resources, the knowledge, and the basis of service and the care coordination skills, to put together models that look at risk identification, disability prevention, rather than a reactive, episodic, crisis-driven model that we're in now.

I realize that we are at the precipice of chaos, but also at the potential for some remarkable change. It is, in fact, this present chaos that we're in that will drive our health care systems and industry to look at what integrated care truly is, to get out of our old acute care episodic box and look at disability prevention and prevention services more than what we have done traditionally in the past.

Clearly these changes aren't going to come from ratcheting down of reimbursement, of denying benefits, but of really rethinking what it is that care is composed of, no longer health care, because that defines you have to have a disease state to access it, but what is the care of patients across a continuum.

Thank you very much.

[The prepared statement of Dr. Phillips-Harris follows:]

*Sutter/CHS*

Northern California's Health Care System

One Capitol Mall  
 Sacramento  
 CA 95814  
 (916) 733-8800

**WRITTEN TESTIMONY**  
**SENATE SPECIAL COMMITTEE ON AGING,**  
**April 23, 1996**

*Mailing Address:*  
 P.O. Box 160727  
 Sacramento  
 CA 95816-0727

Cheryl Phillips-Harris, MD  
 Sutter/CHS  
 Sacramento, California

Mr. Chairman and members of the Special Committee on Aging. My name is Cheryl Phillips-Harris. I am a geriatrician and Director of Clinical Resources for Sutter/CHS Continuing Care Division, Central Region. Sutter/CHS is a not-for-profit, multi-service health care system with approximately 6,000 affiliated physicians in Northern California. Sutter/CHS Central Region is based in Sacramento and encompasses the surrounding four-county area. It includes 6 acute care hospitals, 3 affiliated physician groups, 3 hospital-based subacute units, 3 free-standing nursing facilities (including an Alzheimers special care center) and a PACE (Program of All-inclusive Care of the Elderly) replication site. We are one of the 27 member organizations within the National Chronic Care Consortium (NCCC). The NCCC mission is to serve as a national laboratory to develop innovative care programs for the chronically ill as well as a national resource center in transforming the current national care delivery systems. I am honored to speak to you today about the integration of care for those who are frail, functionally dependant and burdened with chronic illness. My desire is to present, from a provider's perspective, what patient-centered care looks like to the patient, what barriers consumers and providers face in the delivery of that care and components of a model that attempts to address those barriers.

In recent years the term "integrated delivery system" has been widely used. It has often meant fiscal relationships or ownership of various facilities representing multiple levels of care. Occasionally it has defined shared financial incentives through risk-sharing contracts. However, these definitions had little impact on the children of the 88 year-old woman with Alzheimers disease as they struggled to navigate through the maze of acute care driven services, multiple payor rules for each provider, lack of care coordination between levels, and the paucity of community based long term care services.

It is well understood that Medicare and Medicaid are two of the fastest growing entitlement programs and that cost containment is critical to achieving the goal of a balanced budget. Yet, the very structure of these programs contributes to the enormous burden of cost. Care is predominantly limited by facility-specific services (ie: acute care, skilled nursing, physician offices) which leads to redundancies in assessments and limited access to shared information. Care is reactive, crises driven and episodic. Payors, including Medicare, will cover services at lower levels of care only after qualifying acute care services are first used.

Overall, there is little opportunity for flexibility in service delivery and little, if any, reimbursement mechanisms for disability prevention.

Returning to the example of the 88 year-old with Alzheimers dementia; the family may have expressed on several occasions their concern that Mother was falling in her apartment. Under the present Medicare/Medicaid fee-for-service system there is no generalized process for identifying risk. Furthermore, once identified there are very few mechanisms to prevent the fall because payment strategies are built around *reacting* to an event rather than *preventing* it. When the aforementioned patient does break her hip, then the full continuum of care is available; including the emergency room, surgery, acute care hospitalization, skilled nursing care, rehab services and home health. In our attempts to manage costs we struggle with lengths of stay, utilization review and needs testing rather than looking to interventions that would likely have prevented the fall in the first place.

Central to this dilemma is the need to understand the historical focus of health care and, hence, payment mechanisms that drive the present system. Medical care in the first half of the century was acute and episodic. With the technologies that grew out of the post World War II era came an explosion of diagnostic and therapeutic interventions to deal with those acute events. The elderly person who, in days past, would have died due to the first bout-of pneumonia, the first heart attack or stroke, now has a much greater likelihood of survival only to, in many cases, be burdened with the disabilities of chronic disease. Chronic disease now accounts for 80% of all deaths and 90 % of morbidity. Alzheimers disease and related dementias are now the 4th leading cause of death in the over-65 population. The burden of chronic illness is also shifted to families and caregivers. When their resources are exhausted, the "social" problems of chronic disease become the "medical" crises. Interventions must then move into the acute care model that is costly and able to offer little to the overall prevention of functional decline of the patient.

The conflicting incentives in the Medicare and Medicaid payment system lead to a continuous cycle of transfers between health care settings. Back to the example of the 88 year-old woman with Alzheimers disease and now a hip fracture. Once transferred to the nursing home she loses her Medicare part-A benefits because of her lack of progress with rehabilitation, (due to her cognitive impairments). Her coverage is then shifted to Medicaid. Several weeks later she is eating poorly, is mildly dehydrated and develops a urinary tract infection. Although the nursing home could manage these problems, the payment structure means that it's "better" for the facility to transfer her to the acute care hospital for IV fluids, antibiotics and feeding tube placement. Once she's had the qualifying 3-day stay, she returns to the nursing home. Since she now has a feeding tube she is able to remain on Medicare part-A coverage for the full 100 day benefit, and both the family and facility would prefer not to discontinue it because she would then, again, lose her Medicare coverage. It is not until day 101 that a trial of oral intake is initiated.

No one knows the total costs of care for any chronic condition because HCFA and private payors don't collect the data about expenditures across time, place, profession and funding source. Several Medicare/Medicaid demonstration projects have attempted to provide integrated chronic care and track total cost of care over time and site of service with some success.

**Social HMO:** The social HMO (SHMO) model offers Medicare beneficiaries an expanded package of Medicare acute care services and limited coverage of long term care. Services are financed on a capitated basis under Medicare, Medicaid and private premiums. SHMOs have been successful in reducing acute care costs through decreased hospitalizations. However, they do not have any incentive to manage risk across the full array of chronic care services, particularly if the individual requires nursing home care. Therefore, SHMOs, to date, have had little impact on the integration of acute and long term care.

**PACE:** The Program of All-inclusive Care of the Elderly (PACE) provides a full range of primary, acute and long term care services for the nursing home certifiable senior. Care is financed through capitated Medicare/Medicaid and private payment. Approximately 90% of PACE participants are dually eligible for Medicare and Medicaid. There are now 12 replication sites around the country. The collective census as of December 1995 was 2,709. PACE is far from being a major player in the delivery of health care to the entire elder population. It is able to serve only a small number of seniors, and there is no ability to *prevent* disability associated with chronic disease since participants must be deemed frail prior to even enrolling into the program. Both SHMOs and PACE, as with other demonstration programs, are limited by a lengthy waiver application process. Furthermore, demonstrations are implemented in an artificial environment, freezing in place certain research designs and thereby prohibiting modifications as learning occurs. The operations mandated under the waivers frequently have little in common with mainstream providers and are therefore seen as irrelevant.

With the creation of the TEFRA Medicare contracts, "managed care" has moved into the world of senior health care. Although provider groups now have the flexibility of pooled, capitated dollars, their HMO plans have provided little by way of solutions for the frail, cognitively impaired or chronically ill elder. Because of the high costs of care most managed care organizations not only fail to market to this population, but look for clever methods to avoid the adverse selection of enrolling large numbers of frail elders. Most managed care organizations have limited knowledge of chronic disease and few resources in place to coordinate the care. The result is that the high-risk, potentially high-cost elder remains in traditional fee-for-service Medicare/Medicaid programs with the same fragmentation and incentives that drive up utilization and cost.

What health care providers need to deliver integrated, cost efficient care is:

- 1) access to all services throughout the continuum,
- 2) methodologies that can identify potential risk within the population and can assess for person-specific needs,

- 3) care coordination that moves beyond facility-specific discharge planning and utilization review to a process that coordinates care and services across all levels, over time, and between providers,
- 4) flexibility of service delivery that is not limited by facility,
- 5) shared financial incentives that measure the *outcome* of care for individuals and populations over time and across settings,
- 6) linked information systems that share demographic, clinical and functional data between providers.

Several health care systems have taken one or more of these concepts and developed programs for the coordination of care for frail and chronically-ill seniors. At Sutter/CHS Central Division we've developed a model, the Geriatric Care Coordination Program, for our Medicare HMO patients that are linked to Sutter/CHS through the Sutter Medical Group. The program incorporates a risk stratification process by screening all new enrollees. Based on their identified risk levels, various resources are put into place, including patient education and social services. Those identified as high risk are seen by a geriatrics care team (MD, nurse practitioner and social worker) where needs are assessed, care is coordinated and patients are followed longitudinally until problem resolution or disenrollment from the HMO. The team shares information with the primary physician and manages the patient and resources across all levels of care. The limitations of this program are the same as those previously mentioned; the financial disincentive to enroll large numbers of frail elders, and the TEFRA regulations that limit the provision of benefits outside the standard Medicare benefits structure.

#### Recommendations

Based on Sutter/CHS's experience, as well as that of other integrated delivery systems, I would offer the following recommendations:

Move beyond the present demonstration process. While neither SHMOs nor PACE, alone, offer the entire solution, both have proven to be successful programs in integrating frail elder care. They have limited impact because the replication process is so severely restricted by HCFA, requiring years from application to program implementation. Furthermore, when viewed by HCFA as merely demonstrations, the number of providers who are willing and able to provide such services is significantly greater than the small number of waivers released.

Establish legislative authority to grant the waivers to allow more organizations to develop other creative models of integrated care for the dually eligible Medicare/Medicaid population. At the present time a number of states have begun or are interested in such program development. Again, as with the SHMO and PACE waivers, it takes years to work through the demonstration application process and obtain a response from HCFA.

This is too slow and cumbersome to allow states or providers to move quickly into development and implementation to test new methods of chronic care service delivery or to modify current systems that are not meeting patient/provider/payer needs.

Modify the current TEFRA payment policy. Currently, the only risk adjustment for reimbursement under the AAPCC is the institutional rate, which specifies the individual must be in the institution, (yet another example of financial incentives that shift services to more costly settings). Use the examples provided by SHMO and PACE where institutional or risk adjusted rates are used based on *criteria* not by *setting*.

The National Chronic Care Consortium has developed a legislative proposal for restructuring Medicare and Medicaid programs and the interdependence between the two. This proposal, the Chronic Care Act of 1995, would establish a simple, consolidated provider category called a chronic care network which would pay for services under an single, pooled financing mechanism, and would be driven by a single set of administrative requirements, payment policies, reporting requirements and methods for evaluating performance. To become a chronic care network, provider groups would be required to demonstrate their ability to integrate a full range of preventive, primary, acute and long term care services, as well as the administrative and clinical systems to support the network. They would be required to demonstrate the ability to integrate care management, quality assurance and information systems. The Chronic Care Act would produce cost savings in several ways:

- 1) improved care and outcomes
- 2) eliminate duplication and fragmentation among services
- 3) streamline regulatory requirements
- 4) establish spending caps
- 5) serve as a "laboratory" for the development of strategies that can improve the systems of services for the chronically ill.

In short, care for the chronically ill would become person-centered, with improved access, decreased fragmentation, provide expanded services and at a lower cost.

I would like to express my appreciation to the Chairman and members of this committee for giving me the opportunity to speak before you today. Sutter/CHS and the NCCC recognize the work that you, Senator Cohen have already done by incorporating major portions of the language in the Chronic Care Act into your bill, SB 2122. I look forward with enthusiasm to the immediate future and our opportunities to redesign the way we serve our nation's frail elderly and persons with chronic illness. We will not change how we deliver chronic care by making small, incremental changes, by ratcheting down reimbursement or by reducing benefits, that will only serve to further limited access and to fragment the care. We will succeed by rethinking how we take care of people with chronic disease and creating new *systems* to deliver that service.



The CHAIRMAN. Doctor, you've given us a lot to think about this morning. As you were testifying, I kept thinking to myself, we are in a situation now where we are debating Medicare and Medicaid. The systems are going broke fast. In 6 years, Medicare is gone as far as its solvency is concerned. So we are faced with two choices right now: do we, in fact, slow down the growth of Medicare from 10.5 percent down to 7.5 percent or 8 percent? That's one option. The other is, according to the trustees of Medicare, to increase the payroll tax by 45 percent. Try selling that one to the country at this point.

So those are the two choices we've been looking at, and what you're suggesting is that we really have to scrap the whole system and say that chaos has descended upon our heads and this system no longer works.

We're looking at that chart over there. I've been staring at that chart. As long as I've been on the Aging Committee, since 1975 when I started on the first Aging Committee in the House, if I had a problem with a family member, the first person I would call would be Mary Gerwin, who's sitting behind me, or Vickie Blatter or Priscilla Hanley. I wouldn't have the slightest clue on where to go, as long as I've been dealing with these issues.

What does the average person do? What does the average citizen do, saying, "Who do I turn to?" Then you start the whole series of phone calls. Do I call my local Congressman or Congresswoman? Do I call the State offices of an ombudsman? Is it part A? Is it part B? Is it in-home service? Is it medical? Is it not medical? Is it mental, as if mental illness is not—

Dr. PHILLIPS-HARRIS. Less important.

The CHAIRMAN. We had a hearing a few weeks ago on depression, and—Mr. Ryan, I see you are still here—we had Mike Wallace who came and testified.

It was a fascinating hearing, because what we're talking about is something you just touched upon, Doctor, and that is that if you have depression you are more likely to suffer physical injury, especially as you get older.

On the other side of the coin, if you suffer physical injury as you're older, you're more likely to get depressed.

It is a vicious cycle that we face as far as the connection between mind and body, and it's not only with the elderly, it's with younger people, as well.

Fortunately, last evening I was tuning in, doing a little surfing, and I found the Larry King Show had Mike Wallace and Art Buchwald and a host of other people talking about the subject matter of depression, getting wide circulation. So maybe we're kind of a precursor to the Larry King Show.

We haven't had any focus on Alzheimer's since Ronald Reagan disclosed that he had it. Then you had a flurry of articles in "Newsweek" and "Time Magazine," they all talked about Alzheimer's. Now it's off the charts. We've got to get it back on the charts.

But I don't see how we can fix our current system by trying to put it in Medicare or Medicaid or maybe have a little more flexibility here, or can you integrate the system. I think you've really got to scrap the system and start over.

If I had the time, I would go through and say, "Each one of you, if I asked you to start over, how would you create the world? How would you create the world of health care in a way that makes sense for the future?"

It seems to me that's what we've got to do. We're kind of playing with it right now in the short term in the political aspects of it. Can we slow growth to 7.5 percent or 7.8 percent, or how are we going to deal with it? We're going to get by the election. What's going to happen? Nothing's going to happen until after November because no one really is willing to face up to this issue of how we're going to continue to pay the cost.

Very few have put the amount of time in that's necessary to call our best thinkers in the field of medical care and say, "How do we construct a new system?" because the current system cannot be sustained for long, even assuming that we slow down the growth and assuming we turn to managed care. Once we get into managed care, we've got that other—the ying/yang problem that you've talked about. Yes, it does have unlimited opportunities. We're finally getting into a concept of integrated care for our citizens.

The other side of that, the dark side of that moon, is that we'll place more emphasis on cost efficiency and depreciate the concern about quality of care.

So it has opportunity, but also some real liabilities there unless we structure it in the right fashion.

Frankly, I don't think many of us, if any of us, at the Congressional level have really thought long and hard enough about it in terms of how we get there. Assuming we can conceptually get there, how do we get there politically? We haven't even begun to deal with this yet. We're still looking at numbers, and we say, "Well, it's 5 years away, 6 years away, or 10 years away, or four decades away. We don't have to deal with it now."

So the crunch is coming, and it's not very far off, but maybe we really have to go through a crisis before you can alter the way things are to the way they really have to be in the future.

Again, I don't have time to explore all that with you, but I think it's at least providing a basis of calling attention to this issue.

We talk about integrated services, but most Alzheimer's patients are at home. Most of the people are at home and their caregivers have no Medicare, no Medicaid, no private insurance, and they're coping as best they can.

I've got a news account here. We've got two people missing just this past week at home in Maine—they've wandered away. The Alzheimer's Association is helping out. They're helping out in trying to cope with this particular issue. I assume that's happening nationwide, as well. We've got people at home who simply don't have any sort of institutional participation in this.

Dr. PHILLIPS-HARRIS. I think the naivete of our present system is that those patients are then no longer our concern because the caregivers are taking care of them.

First, that's an immoral stance. Second, they become our concern because then what happens is those social issues become medical catastrophes for which we have a number of DRG's to bill under.

If we don't provide the resources for the caregivers, then those who wander off, who are lost, who have hip fractures, who don't

eat, who fall, who have wounds, become the medical problems that drive our cost.

So it is truly naive to think that, because a large segment of chronically-ill patients are not relying on Medicare or Medicaid, that they are not part of the cost basis. In fact, they're part of what drives the cost basis.

The CHAIRMAN. I thank all of you for your testimony. It's very helpful. Hopefully we can call the attention of our colleagues to the importance of this issue. It is going to affect virtually every one of us in the years to come, if not in the immediate future.

Your testimony has been very helpful. We will see to it that it is circulated and we will argue the case to the Finance Committee, which has jurisdiction, as you know, over the entire Medicare and Medicaid programs.

I thank all of you for coming and spending so much time here this morning.

The committee will now stand adjourned.

[Whereupon, at 12:25 p.m., the committee was adjourned, to reconvene at the call of the chair.]

## APPENDIX

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APRIL 19, 1996

The Hon. WILLIAM S. COHEN  
*322 Senate Hart Building, Washington, DC.*

DEAR SENATOR COHEN: When we met 23 years ago at the Capitol, neither you nor I knew that Alzheimer's disease would become a scourge that would some day afflict 4 million Americans, including 37,000 in the Greater Washington area. We certainly never thought about it happening to one of us. But, as you know, the disease began its slow and imperceptible process with my wife some 6 years ago and now she is no longer with us.

We were blessed over the years to have the concern and support of friends, like you, as the disease progressed. We know when Alzheimer's ends but when does it begin? Those who have it are not aware that anything unusual is happening and the hapless caregiver, if he or she has a clue, essentially wants to deny it. The advance is painless until the symptoms manifest themselves in ways too obvious for the caregiver to ignore.

In retrospect, I realize that I was rather casual and not ready early-on to accept the fact that something was happening to this physically strong, vibrant person who had made her mark in television and in every conceivable volunteer effort in Washington. When the brain imaging led to the presumptive diagnosis of Alzheimer's, I did not tell her because I did not want to frighten her and our routine at home had not changed greatly. She was still capable of preparing meals and enjoyed dinner with friends and dancing at the Club. But as the months went by, she sensed her limitations, became more withdrawn and let me do the talking, as well as the planning and arranging, including meals. When my gourmet cook deferred to me in the kitchen, I knew it was time to deal with the inevitable.

At this point, I welcomed a call from the National Institutes of Health asking if we would like to participate in a protocol involving a new potentially helpful drug to deal with Alzheimer's. She willingly made the trip to Bethesda three times a week to receive the medication and submit to all manner of spinal taps and brains scans, as well as memory tests. After a few months, the funding for that program ran out and I assume the drug was no longer being pursued. It certainly did not have any tangible effect on her condition. At this point, she once asked me what her problem was. I tried to explain and she said she thought she was "getting better."

But my hopes were quickly dashed as she became more restless and insecure and unable to communicate or recall anything of her

past active life. At NIH, a practitioner told me that her real trouble and mine would begin when she couldn't dress herself. This proved to be true. Without detailing the familiar problems facing family members and in our home where she was comfortable, as long as possible. In due course, we settled, into a routine where I could experience an unexpected satisfaction and contentment in ministering to her needs.

Friends urged me to attend a seminar provided by the Washington chapter of the Alzheimer's Association to acquaint caregivers with its many programs and services. I found their pamphlets and resource books helpful for my understanding of what to expect. But unlike many others, I chose not to take advantage of caregiver support groups. I know how much these meetings have helped friends but I preferred not to sit and listen to the plaintive tales of others. Perhaps that was a selfish view and conceivably I could have offered some consoling advice.

But what I needed most in the crucial mid-stages of my wife's illness was a ready source of reliable, understanding help at home, someone with sensitivity to the disease who could spell me long enough to go to a Press Club luncheon, a gathering of friends, perhaps for a daily walk in the park. I assumed the Alzheimer's Association and other concerned groups would have a list of standby help for the choosing. But it proved very difficult, even impossible, to locate respite help through the obvious channels. On occasion, I would engage a good sitter but she had no transportation and I could not readily leave home to drive her back and forth. Eventually, I was lucky enough to find someone who could not only give me respite but also help with the housework. Fortunately, I was able to afford this regular, steady relief so that I never had to resort to a nursing home or other facilities. But I worry about those who are not as well situated.

There is an urgent need for an organized in-home respite service in every community and it could prove to be one of the most beneficial functions performed by local Alzheimer's organizations. I understand an experiment is under way in Prince George's County with some early success.

My own experience was a happy one in the circumstances. I can't help but feel that, lacking a cure for Alzheimer's which is still far in the future, the best medicine is a comfortable home environment in which the caregiver is able to enjoy regular intervals of relief. Perhaps there's a role here for our churches and the religious community. Your own leadership as we seek solutions in this difficult field is deeply appreciated.

Sincerely,

DON LARRABEE.



ISBN 0-16-052943-3



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