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National Center on Caregiving

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*A legislative hearing before the Senate Subcommittee on Aging and Long-Term Care in Sacramento focused attention on strategies to support family caregivers in California. The session looked at future and current caregiver needs and the unique demographic trends that impact this important public health issue. Dr. Moira Fordyce was a key spokesperson. Below is her testimony.*

Senator Alquist (now retired) and Members of the Subcommittee:

Thank you for giving me this opportunity to speak to you on the important topic of caregivers in the USA. I will be sharing information with you from my years of medical practice.

I have been a doctor for 43 years, and have practiced medicine in Scotland, England and the United States of America. When I came to America in 1976 after 14 years of practice in Britain I was an internal medicine specialist with training in geriatrics. Since at that time there were few geriatricians in the US, I was prevailed upon to practice and teach geriatrics, and I have done this with great satisfaction ever since. I specialized in home visits, nursing home care, and hospice, and set up home care, hospice and geriatric programs for Kaiser Permanente in San Jose. Now my main focus is teaching, writing, research, committee work, medico-legal review and advocating for the elderly and caregivers. I have also joined the ranks of the “young-old.”

Those are some of my medical credentials. I have also been a caregiver to my husband, three sons, and my mother. More of that later.

- The topics I would like to cover are:
- The effects of caregiving on caregiver health
- The importance of listening to the caregiver
- The importance of physician assessment of the caregiver
- The need to educate medical students on the role of the caregiver

## **The Effects of Caregiving on Caregiver Health**

There is now a large and growing body of evidence that confirms that caring for a physically or mentally chronically sick person can have dire consequences for the caregiver.

Caregiver health is becoming a public health issue, as the numbers of caregivers grow and the average duration of caregiving is four years. In many cases, even longer.

Health effects can be physical, mental, emotional, or a combination of all three:

### **Physical Effects**

Compared with noncaregivers, caregivers suffer from:

- Diminished immune responses, which means more frequent infection and increased risk of cancers
- Slower wound healing
- Higher incidence of hospitalization
- Higher mortality rate
- Poorer general health
- Higher incidence of headaches, gastro-intestinal problems and insomnia
- An increased risk of heart disease.

### **Mental Effects**

Compared with noncaregivers, the following occur more often in caregivers:

- Depression and anxiety disorders, and these can persist, even after the death of the patient or placement in a nursing home—guilt often adding to this sad picture.
- Whenever we say “depression” the next thought must be “is suicide far behind?” and yes, there is a higher incidence of suicide among caregivers.
- Alcohol and other substance use—this has serious implications for driving and operating machinery as well as damage to health.

### **Emotional Effects**

- Emotional exhaustion and caregiver stress is real and debilitating. Among signs of caregiver stress are anger at self and the patient; social withdrawal from friends and activities previously enjoyed; irritability leading to moodiness; negative thoughts and reactions; inability to concentrate; and errors at work—the wage-earning caregiver cannot afford this.
- There is evidence now that emotional stress adversely affects longevity—this goes with the higher risk of mortality I have mentioned above.

Physical, mental and emotional damage, or a combination of all three? What a gloomy picture! But is it always like this? Does it need to be like this? I am happy to say the answer is “No!” it needn’t be like this.

We can change it, ladies and gentlemen. Sick caregivers cannot effectively look after chronically sick patients so we must find ways to keep caregivers healthy. How might we do this? As well as the studies supporting the adverse effects on health I have described above, there are other studies that make it abundantly clear that access to a good social support network—family and friends, community resources, religious groups, volunteers—and respite care have a strongly positive effect on the mental, physical and emotional health of the caregiver.

**Respite Care** can range from a family member, friend or volunteer coming in for a few hours each week to give the main caregiver a break, to having the care recipient attend a day care center, to admitting him or her to a nursing home for a few days to hiring in-home help. Respite care is caring for the caregiver.

## Fragmented Support Systems

How can caregivers access much needed help? This, alas, is one of the major problems. There are many good resources available all over the US, but fragmented. I can’t help comparing our system with Britain, and the time when my mother became ill. It was a sad time, because she was one of the unlucky ones—she developed cancer and it was diagnosed too late when it had spread widely. She had felt bad for months, but told no one. My mother spent the last few months of her life on hospice, and access to it was so easy.

- A public health nurse was available at all times.
- Home visits were made by the doctor at regular intervals.
- I could obtain any equipment we needed at the local Red Cross office.

This high quality care National Health Service meant: there were no reams of paperwork; no cost to my mother or to us; worry over finances didn’t exist.

A somewhat similar system exists at Kaiser Permanente—when I worked there I had easy, one-stop access to obtaining resources for my patients both inside Kaiser and in the community, and there were medical social workers and a home care team. But, outside such a system...?

There was an article in the New York Times a few days ago, called “When Experts Need Experts,” describing the saga of two of the most respected national and international figures in Gerontology and Geriatrics, Robert and Rosalie Kane.

When their elderly parents needed help the Kanes found great difficulty in navigating the stormy, shark-infested seas of long term care. As a result of these experiences they have formed a 600 member organization called “Professionals with Personal Experience in Chronic Care” and have had a book published recently, called *It Shouldn't Be This Way: The Failure of Long-Term Care*. It is part memoir, part guidebook and part call to arms. If two experts in the field found it so difficult to organize care for their parents, what hope is there for the diverse 77 million aging boomers and their caregivers?

It shouldn't be this way—it needn't be this way—we must fix our fragmented system. We must find a way to make access to available resources easier for caregivers.

## **The Importance of Listening to the Caregiver**

Caregivers are our early warning system and must be listened to—studies show that in patients with dementing illnesses, such as Alzheimer's dementia, caregivers are right about change of condition in the patient more often than the health professionals, even if those health professionals are seeing the patient on a regular basis. We ignore caregivers at our peril. We must listen when they speak. One of my nursing home patients illustrates this well—Joe was 77 years old with Alzheimer's dementia. When he started lashing out and hitting everyone it was the aide, his caregiver in the nursing home, who gave us the diagnosis. She observed that it was when anybody or anything got near his mouth he went ballistic. He had developed a painful dental abscess. Thank heaven we listened to her, and that she was comfortable speaking to us, and his pain was relieved with treatment.

## **The Importance of Physician Assessment of the Caregiver**

We must keep caregivers healthy—we are hugely in their debt. A simple question “Who is the main caregiver?” can start a caregiver assessment.

Although overall women remain the principle caregivers “holding up the sky,” men are becoming more involved, and have special issues as caregivers in addition to the health issues mentioned above:

- Giving personal care to a parent can embarrass them, and their parent.
- They can be reluctant to admit they are caring for an elderly relative.
- This in turn can mean they don't seek needed help.
- They don't talk with friends about caregiving.

They don't join support groups as readily as women do, though there are now some support groups especially for male caregivers.

Next, health professionals should ask the caregiver about her own health, how does she rate it, what help does she have, and, depending on the answers to these questions, can move on to more specific health inquiries.

I can hear doctors complaining that "It's all very well, but this takes time, and time is money!" I know, from years of doing it, that the better the initial evaluation of both patient and caregiver, the more time is saved in the long run. Not just time saved, but money, too, as a result of:

- Improved health
- Fewer costly medication errors
- Fewer costly ER visits
- Fewer costly acute hospital admissions.

## **The Need to Educate Medical Students on the Role of the Caregiver**

Medical students need this education. The physician assistant students I teach every year at Stanford are savvy about this; nurse practitioners and nursing students are too, as are the other members of the health care team, the medical social worker, and the rehabilitation folks. They all understand the importance of the caregiver in any chronic illness.

A few years ago I put together a panel program for medical students at Stanford. Other health professional students were encouraged to attend. I developed a case study, typical of many of my patients, of a 78-year-old woman who has a stroke and is admitted to hospital. Her sole caregiver is an 83-year-old husband. Their children all live far away. She is discharged from hospital to a nursing home for rehabilitation, then home to the care of her frail, elderly husband. Before long she has a second stroke, is very ill indeed and is admitted to hospital, then hospice, first in a special hospital ward, then at home where she dies two weeks later. On the panel I played the part of her doctor; the nursing director of one of the best nursing homes in the area and a medical social worker completed the team.

We did case management on this lady as she moved from one setting to another—how could her frail caregiver spouse receive needed support, then after her death, how could he be helped, with audience participation encouraged throughout. The presentation was a huge success. The students didn't want to leave when it was finished—they clustered around us and what I heard

from one after another was “That was great. I have never thought about what happens to the patient after she leaves hospital.” They knew about acute care, yet most health care in America is chronic care.

We must teach medical students about the importance of evaluating, educating and helping the caregiver in every way possible. It’s well known, sad to relate, that medical students’ attitudes toward elderly people deteriorate significantly during their years in medical school. We must change this. We must teach our medical students about elders and their often heroic caregivers, and change their negative attitudes. We must link them with robust elders in the community to give a more balanced picture of aging. We must not cut back funding for training programs in geriatrics—we already have too few geriatricians.

## In Conclusion

Being a caregiver in America in this new millennium ain’t for sissies! Health can be impaired by caregiving, accessing help is difficult, caregiver contributions to our society are undervalued.

We must care for the caregivers—we are all indebted to them for the unpaid work they do. We have the wherewithall to help. We have the resources, but they are fragmented—we need to come together to be effective. We have the expertise, as long as funding for geriatric training programs isn’t cut.

Thank you for your time and attention.

Thank you for caring.

*Dr. Fordyce is President, California Geriatrics Society (State Affiliate, American Geriatrics Society).*

*We thank her for her participation in this important hearing.*

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