

Voices For Change

Health Care Professionals Share War Stories

More than 50 health care professionals responded to our initial request for detailed “war stories” describing the personal care delivery challenges they or their family members have encountered with the health care system they work in every day. These personal stories address problems encountered in both acute care and long-term care settings and convey a common frustration and feeling of guilt over their inability to navigate in an environment where they have considerable expertise.

The “war stories” we have received so far address issues including:

- Caring for elderly parents
- Transition from hospital to nursing home
- Lack of palliative care
- Persons with their own chronic illnesses who must care for aging parents
- Coordinating mental health services with medical care
- Coordinating care over a long distance
- Negotiating with HMOs to cover chronic illness care
- Caring for children with disabilities

Upcoming quarterly issues will feature a selection of these personal stories to help inform both health care professionals and educate public policy leaders about the need to reform our health care system. (See Page 2 *In My Words* article.)

If you have a compelling story to share, send it to me at kanex001@umn.edu.

You can also join our listserv by emailing us at ppecc-members@lists.umn.edu.



PPECC's Mission

Robert L. Kane, MD

- Tap the unique credentials of health care professionals as both care recipients and subject matter experts to improve the delivery of chronic illness care.
- Chronicle health professionals' personal experiences to formulate policy proposals and advocate for change through legislative testimony, media relations and public conferences.

Prevalence of Multiple Chronic Conditions

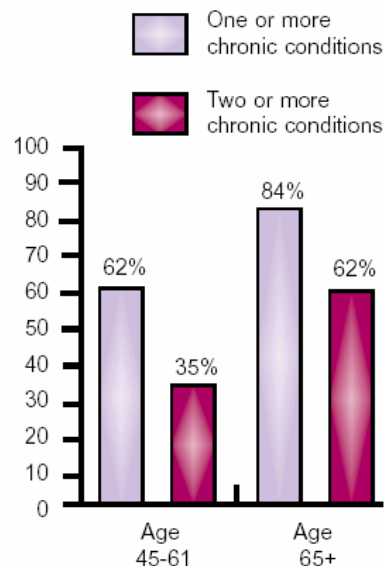
As people age, the chance of developing multiple chronic conditions increases. Sixty-two percent of adults 45-64 have one or more chronic conditions, and 35% have two or more chronic conditions.

These percentages rise drastically for those 65 and over. Eighty-four percent have one or more chronic conditions and 62% have two or more chronic conditions.

People who experience multiple chronic conditions report that they find it difficult to pay for care. A recent survey found that the three things people feared most about having multiple chronic conditions were:

- The inability to pay for care
- A loss of independence
- Having to burden family and friends with their care

Chronic Conditions: Making the Case for Ongoing Care
 Prepared by Partnership for Solutions
 Johns Hopkins University, for The Robert Wood Johnson
 Foundation December 2002



In My Words... by Lyndon Drew, Gerontologist, Wichita, KS

My father died in 2003 after battling diabetes and its complications. Medical mismanagement robbed him of all but a few good days during his last months of life. As a gerontologist, I learned the hard way that the long-term care system sometimes does more harm than good. I promoted better mental health and aging services for 10 years as a staff member for the Kansas Department on Aging. Now I have seen the dark side, the abuse of readily available psychotropic drugs. These drugs are meant to counter the symptoms of mental illness, but they can instead rob older adults of their mental abilities and increase their dependency on the long-term care system.

My father's last days began in the hospital emergency room and intensive care because his blood sugar dropped to 20. His physician also diagnosed a urinary tract infection and prescribed Noroxin, an antibiotic. My father recovered from his low blood sugar and moved out of intensive care. Unfortunately, he quit eating. His lunch from a full tray of hospital food, too often, was a serving of jelly. He would reject everything else, declaring, "I'm not hungry." Hospital staff discussed with family the alternative of assisted living, but his wife chose to take him home and assume the role of caregiver. The hospital discharged him starving to death.

He went home with home health care, his Noroxin, and a prescription for Humalog (a form of insulin). The family and the home health nurses tried various approaches to treating the starvation. Usually he cursed them and refused all food. Family members theorized that he might be depressed, so the physician gave him free samples of Zoloft, an antidepressant. The Zoloft made him sick. He started to throw up what little food or drink he had consumed. The physician offered another drug to control the side effect of the Zoloft. We threw the Zoloft in the trash. The Zoloft experience had raised a question, "What are the side effects of Noroxin?" One side effect of Noroxin is a loss of appetite. The family decided to

stop the Noroxin and buy milk shakes on the advice of a dietician. My father started eating. Within a week he was laughing and living. He survived his first encounter with the dark side of mental health and aging. The family discontinued home health care. In my last phone conversation with the nurse, I suggested that my father's starvation was drug induced. The nurse never acknowledged that I had spoken. The case was closed. Normal life resumed for a few months until one day my mother reported that my father was falling and could hardly walk. The hospital admitted him pending an MRI to diagnose the stroke. My father entered the hospital coherent, but once in the hospital he became incoherent. He often asked for help to get out of bed, to leave his room, to wander the halls. The hospital eventually transferred him to a private room across the hall from the nurse's station. Fortunately, he recovered his wits after a few days. By Sunday morning, he was different; he was sluggish, less coherent. I asked the nurse if he was taking any new drugs. She said yes, Celexa (an antidepressant). I objected, but the medical professionals thought the drug might make physical therapy for the confirmed stroke more possible. By the middle of the week hospital staff had to manhandle him just to get a sugar count. The family then agreed to refuse the Celexa. I wrote on the room blackboard, "No Celexa." The nurse and the physician got the message.

A pain in his leg landed him in the hospital a third time. The emergency room physician diagnosed gout but an unusually low heart rate prompted hospitalization. The next day, nurses started giving him Xanax (an anti-anxiety drug) without the family's knowledge. He started asking for help to get in and out of bed, to leave his room, to wander the halls. Hospital staff wanted family members to stay with him throughout the night. The family learned about the Xanax and immediately asked nurses to discontinue dosages. My father's restlessness decreased. A new physician, a cardiologist, diagnosed advanced congestive heart failure,

too advanced for treatment. My father had entered the hospital with misdiagnosed ischemic pain and left with hospice care.

The family now understood that my father had missed his opportunity for treatment of a chronic illness and had suffered again and again from treatment for mental illness - with Zoloft when Noroxin robbed his appetite, with Celexa when a stroke took his mobility, with Xanax when congestive heart failure created pain and confusion. During his last days he got Loratab from the hospice whenever he needed a painkiller. The hospice social worker also suggested an antidepressant when he talked about his deceased brother. The hospice nurse brought Lorazepam for his anxiety. He subsequently fell, a possible side effect. So from the beginning to the end of his long-term care, my father suffered from drugs meant to help his mental health.

Research verifies that my father's experience was not unique (AHRQ, 2003a; McCoy, 2002). I used to worry that older adults underutilized the mental health system. Now that 20% of older adults are using psychotropic medications, I worry that older adults are overutilizing mental health services (AHRQ, 2003b). Chemical restraints are regulated in nursing facilities; but they are readily available outside of nursing facilities. Medical iatrogenesis can take advantage of this availability to create drug-induced dependency in older adults living in the community.

I have already written a letter to my son advising him that if I suffer the same fate as my father, he should spare me the psychotropic drugs. Just give me more tomato juice. It seemed to help my father's mental health when all else failed.

(Article references listed on page 4)

Assisted Living...What's in a Name? by Robert L. Kane & Joan C. West

Our mother took great pride in her independence. Her greatest fear was becoming disabled. Unfortunately, this fear was realized when she had a stroke in May 1999 at the age of 84. She had shown some signs of memory loss and confusion prior to the stroke but these problems became central thereafter. She recovered an amazing amount of function after rehabilitation and was able to walk and perform most activities of daily living on her own. Given her level of functioning and our aversion to nursing homes we decided that she was well suited to assisted living.

People assume assisted living can replace nursing home care, but that is not usually the case. The range of services available at what we will call ALFI was more suited to frail older persons who had decided that the effort required to maintain their homes was too much but who were still quite capable of looking after themselves. A substantial proportion of the residents used canes or even walkers, but with these devices they could function independently.

Although assisted living implies the merger of care with a comfortable living environment, this was not the model we discovered we had bought into. The facility's expectation was that despite our paying for a basic set of services, we would hire outside help to look after our mother as it became necessary. This pattern of having aides in ALFI was very prevalent. Several residents had 24-hour companions who were a common sight in the lobby or at the various activities. There was always tension between many of the regular staff and the hired aides as to where the responsibility of one started and other ended.

Our use of outside aides began as a part-time supplement to give Mother more one-on-one attention. We first hired a companion for the afternoons. These aides were not really certified aides, but were just a couple of women who could devote a few hours a day for three days a week to keep Mother company. Then we moved to weekend aides, because it was helpful for Joan to have someone who could stop by for a few hours on the weekend so she would not have to keep running back from her weekend home. Next it seemed a good idea to have someone to get Mother dressed just be-

fore lunch and oversee the lunch hour. Mother's appetite was very poor when she was depressed and we thought that she would do better with a little one-on-one encouragement.

About six months after entering ALFI, Mother experienced the first of a series of hospitalizations for congestive heart failure. The ALFI nursing staff (who were not registered nurses) became very nervous if she said she could not breathe. Most of the time she was exhibiting anxiety symptoms, not congestive failure. But one day she did have congestive heart failure. Joan and her husband took her to the hospital. This became a pattern.

The use of aides came on gradually. After each hospitalization her return to the ALFI was not easy for her. At one of these transitions hiring aides seemed a viable solution. Early in her course we had hired the aides for only a day or two to facilitate the transition back to the ALFI. After about a year we hired an aide to work as her aide/companion and to assume much of the day-to-day responsibility for her. Taking this step undoubtedly made our mother more dependent. More than needing the help, she loved the attention. Joan still continued to visit her almost every day.

Even when she had an aide during the days the problems continued. Mother would experience panic attacks when the aide left at. Mother called Joan almost daily after seven each night. Sometimes telephone reassurance sufficed but on numerous occasions Joan had to return to ALFI to calm her down. As Mother's condition deteriorated we were buying the services of both a daytime and nighttime aide. However, the night aide was not doing anything to affect her wandering or controlling her disruptive behaviors and we decided to cut back to one 12-hour daytime aide. As her condition deteriorated, the facility put pressure on to have an aide during the nighttime. This meant we were paying for care more expensive than a nursing home.

We were paying the aides at a rate of \$12 an hour. We pointed out that we were already paying for a set of assisted living services that now included extra payments for incontinence care. They said that this was the only condition under

which they could allow her to stay. We reluctantly acquiesced for the short-term but finally realized that we had to make a move. As things turned out, Joan and her husband were moving farther out on Long Island. We decided to transfer Mother to another assisted living facility known for its special dementia care. Indeed, Bob and his wife knew the owners and alerted them to Mother's case. Despite these efforts to establish a strong working relationship with the new facility, Mother's condition declined with time. She spent nine months there hating being among "crazy people." Ultimately she became more than they could manage and she entered a nursing home, where she died after three months.

Each step was harder for all of us. Despite our best efforts, nothing about this experience reflected the way she wanted to end her life. All the way through this depressing experience we kept asking ourselves if this was happening to us, who knew how the system works, what must it be like for those who enter it uninformed and ill prepared. Looking back over this experience it was not the way any of us would have wished it. Mother lived the life she dreaded. Joan found herself unable to ever do enough and miserable watching her mother decline in front of her. Robert was frustrated with his inability to make the situation work. All of the theories about how different types of care were supposed to respond to changes in an older person's life simply fell apart despite his best efforts to find the best providers of care and to help them develop effective approaches.

Despite advocating empowering older persons, we wound up making all the decisions, even when they clearly violated our mother's wishes. She wanted to live on her own (or really with 24-hour supervision) in an apartment. We felt that such an arrangement was too tenuous given her inability to sustain relationships with people who worked closely with her. Creating a new living situation from scratch would have been very difficult and costly, but we never tried to make it work. In the end, we are left feeling that the end of life should not have to be this way

Professionals With Personal Experience in Chronic Care

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RETURN SERVICE REQUESTED

PPECC — Driven By Member Participation



We encourage you to share your personal experiences in this newsletter and we welcome your suggestions for events and activities PPECC should undertake in the future.

Email your stories and ideas to PPECC at kanex001@umn.edu or you can send them to:

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In My Words...Article References

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