

## When a “No Nursing Home” Promise Must be Broken

“I’ll never let them put you in a nursing home. I promise I’ll always take care of you at home.” Many couples exchange such tender and sincere declarations while both partners are still of sound mind and body. But when an aging spouse undergoes a personality change, commitments of this kind can exact an enormous price from the healthy spouse.

After Bill’s retirement five years ago, for example, Edna noticed that her husband’s personality had slowly changed. Always a forceful and well-organized man, Bill had retired as the head of a multimillion-dollar corporation. But the sparkle had gone out of Bill’s eyes, leaving a blank stare in its place. He had taken to calling their friends and annoying them with endless, rambling conversations that harped upon two or three disjointed topics. It was as if his cerebral function had, like his arteries, become narrowed and hardened. Bill’s behavior put a strain on many of Edna’s friendships, and she came to feel increasingly isolated.

When Edna came in for routine exam, she appeared frail and distraught. Once vigorous and hale, Edna had begun to show signs that her own health was breaking down. I asked how things were at home. Edna gave a long sigh and hung her head. She told me she loved her husband and that she had promised him many times she would take care of him at home. She had been getting some help from a home-care aide, but that arrangement no longer seemed sufficient. When I pressed the point, she said – a little tearfully – that she didn’t know if she could keep going the way things were. Then she looked up at me and asked, “Doctor, what happened to the man I married?”

It was clear to me that Edna had reached a time when it was no longer possible for her to care for her husband at home. But almost without exception, a decision to institutionalize the ailing spouse provokes devastating feelings of guilt in the healthy partner – even if such a decision is clearly the best for all concerned. Often the caring spouse is overwhelmed by a sense of failure, of disloyalty, even of betrayal.

In my 35 years of practice, I have found that many couples exchange promises like the one by which Edna had felt bound. But such contracts can imprison a healthy mate in an unhappy and one-sided relationship. Healthy partners may sacrifice their own well-being – and sometimes even their own health – for the care of loved ones who may no longer even recognize them.

While a dilemma such as Edna’s is a matter of very personal judgment, I believe that promises exchanged by healthy spouses must be reevaluated when one partner undergoes a change in personality. And we can offer meaningful assistance to the mates of such “changed” elders. Such spouses may, like Edna, need the opportunity to discuss a very difficult decision. They may need reassurance that there is no dishonor in getting help – even institutional care. Or they simply might need help recognizing that a changed personality may require a change in caregiving arrangements.

A personality change can be associated with psychosis, dementia, arteriosclerosis, or some other illness or injury. Often the change in personality is accompanied by physical problems that make home care even more difficult for the unaffected spouse.

The husband of one of my patients, for example, was having a hard time taking care of his wife after her stroke. Once a loving wife, Melba had become demanding, obstinate, and abusive – all of which was a trial in itself for Jim. But Melba also became incontinent, and Jim found it nearly impossible to deal with the constant soiling of her clothes, their furniture, and their floors. But like Edna and Bill, Jim and Melba had exchanged promises that they would care for each other at home, whatever happened. Now Jim felt locked into a contract with a woman who bore little resemblance to the wife he had known and loved.

Perhaps if Melba's personality had not changed, Jim would not have found it so difficult to deal with her incontinence, but the combination was defeating him. He needed to be reassured that placing his wife in a nursing home did not amount to abandonment or betrayal.

In some cases a change in personality can wreak havoc with a spouse's well-being. Another of my patients found that dealing with her husband's Alzheimer's disease required a thicker skin than she possessed. Lillian stopped feeling comfortable in public with Carl after he made a scene at a church social – accosting everyone he met to “play some blackjack” and making suggestive comments to many of the women in the congregation.

In addition to acute embarrassment, Lillian felt an acute sense of loss. Not so many months before, Carl had been an attentive husband and a highly respected member of the community. But because of his dramatic change in personality, Lillian was having a hard time caring for Carl at home. Yet she had promised Carl long ago that she would never put him in an institution. Could she, in good conscience, place him in the full-time care of a nursing facility? Until we began to discuss the matter, Lillian had been unwilling even to entertain the possibility.

Although I certainly don't consider it my province to tell patients how to handle important personal questions such as these, I do try to offer them the opportunity to discuss these matters in an open and non-judgmental manner. And I often ask patients like Edna and Jim and Lillian to think about what they would consider appropriate care if the situation were reversed. Would they really want to put their own loved ones through the hardship of caring for them at home? Would they want others to feel guilty about placing them in a nursing home if they were to undergo radical changes in personality or level of functioning?

The spouse of an afflicted partner may welcome the chance to discuss his or her situation with you. And healthy partners may be greatly relieved to have you point out that – at least in some sense – they are now dealing with a different person from the beloved partner they had promised to look after at home.

Certainly it isn't our role to tell people how to live out their commitments to others. But in dealing with the companions of older patients whose personalities have changed, we can raise the possibility that some kinds of promises may become untenable. When older couples have exchanged promises to care for each other at home, we can help them see the limitations of such agreements. And we can reassure the healthy partner that there is nothing shameful in admitting the need for help. In doing so, we may be lifting an unbearable burden.

For more information, please contact the Alzheimer's Association, Southeastern Wisconsin Chapter Helpline, toll-free at 1(800) 272-3900. Assistance, information and support is available 24 hours a day, seven days a week.

