

The CALL THAT'S COMING

BY JIM COMER • PHOTO ILLUSTRATIONS BY FRANK CURRY

If you remember nothing else from this article, let it be this: Talk to your family about the issues of aging before there is a crisis. **Procrastination is your enemy.** There will never be a perfect moment to bring up the subject.



At 7 a.m., my phone rang and I heard the voice of Lisa Huff, my parents' next-door neighbor in Dallas.

ON THE MORNING OF February 20, 1996, I lived in Los Angeles, had a good corporate job with excellent benefits, enjoyed a caring group of friends and sang in the church choir. I had been in California for 13 years and thought my life was stable. I was mistaken.

At 7 a.m., my phone rang and I heard the voice of Lisa Huff, my parents' next-door neighbor in Dallas. In 34 years she had never called me. I braced myself for bad news, and she produced it promptly.

She told me that my dad was walking up and down in front of the house as if he were in a trance. She thought he was having a stroke. Lisa's sidewalk diagnosis proved correct. Caring for my mother, who had early Alzheimer's, had taken its toll on my 86-year-old father. Within hours he was in intensive care, I was on a plane to Dallas, and my world changed forever.

When I walked into the hospital room, I could hear my parents' friends breathe a collective sigh of relief. The only child, the surviving son, was back. The man with all the answers had arrived! If only that had been true: I didn't even know the questions. Now it was too late for the conversation we never had: Dad couldn't talk, walk and had no control of his bodily functions. Mother was confused, unsure of what had turned her life upside down.

Though it was time for me to take charge, I didn't have a plan or the most basic information I needed. During my twice-yearly trips home, Dad and I talked about "important" things like the Dallas Cowboys or who should be elected president. I knew how he stood on the federal deficit but had no idea about his own investments.

Every time I asked a question about Mother's condition or mentioned the possibility of their selling the house and moving closer to his sisters, Dad would leave the room. And I let him get by with that year after year! Why didn't I follow him, let him know that I wanted to be there when they needed me, but couldn't help if he wouldn't talk to me? Instead of confronting my dad, I remained a polite Texas son, he stayed in denial, and we talked about football instead of the future.

Suddenly faced with making scores of decisions, I had to start from scratch. I had never seen their wills or the contents

of their lock box, didn't have powers of attorney and had never discussed end-of-life decisions. I knew little about their finances (other than how much they'd lent me) and nothing about their insurance. It turns out they were insured for everything except long-term care.

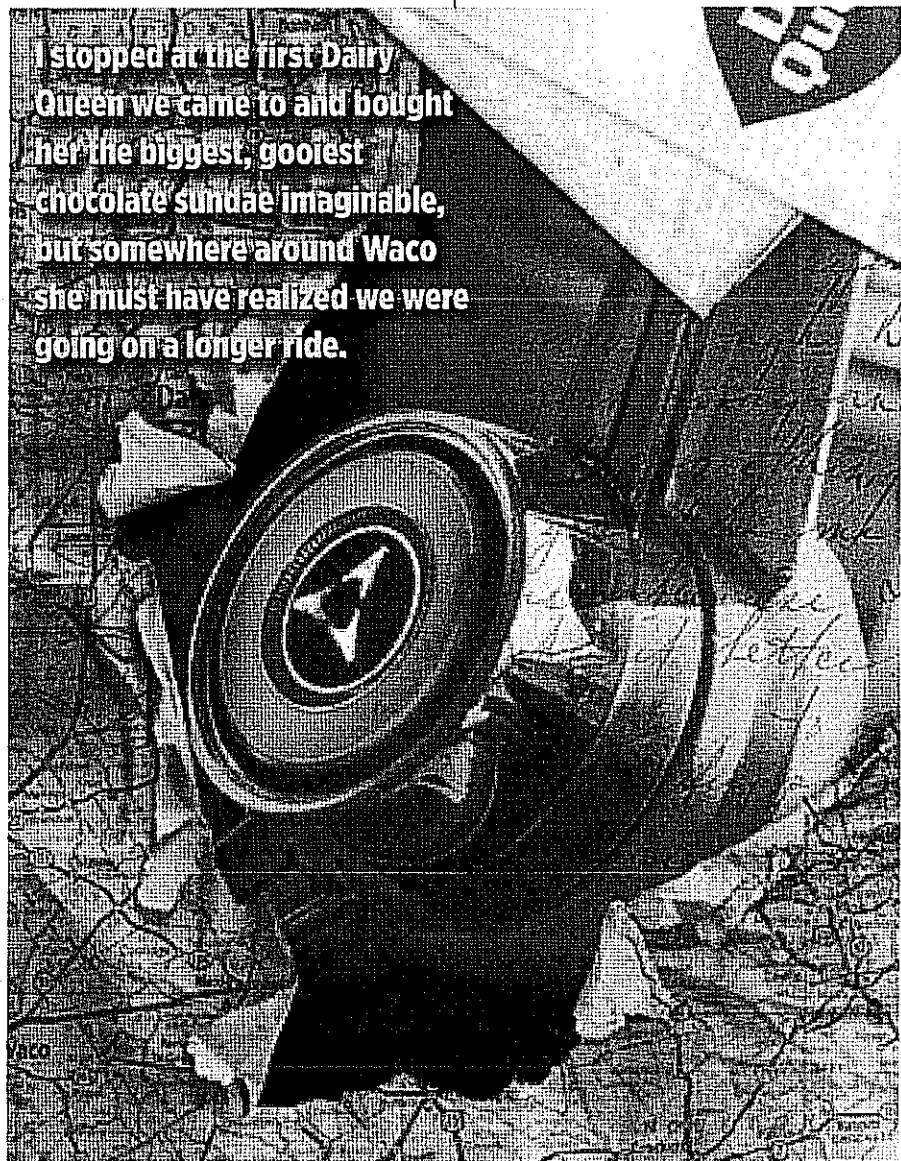
The hospital officials wanted Dad out in one week. I had just seven days to find a rehabilitation center where he might possibly learn to walk and talk again. I knew they couldn't stay in Dallas, as most of our family was in Central Texas. In a crisis, friends are wonderful but family is essential.

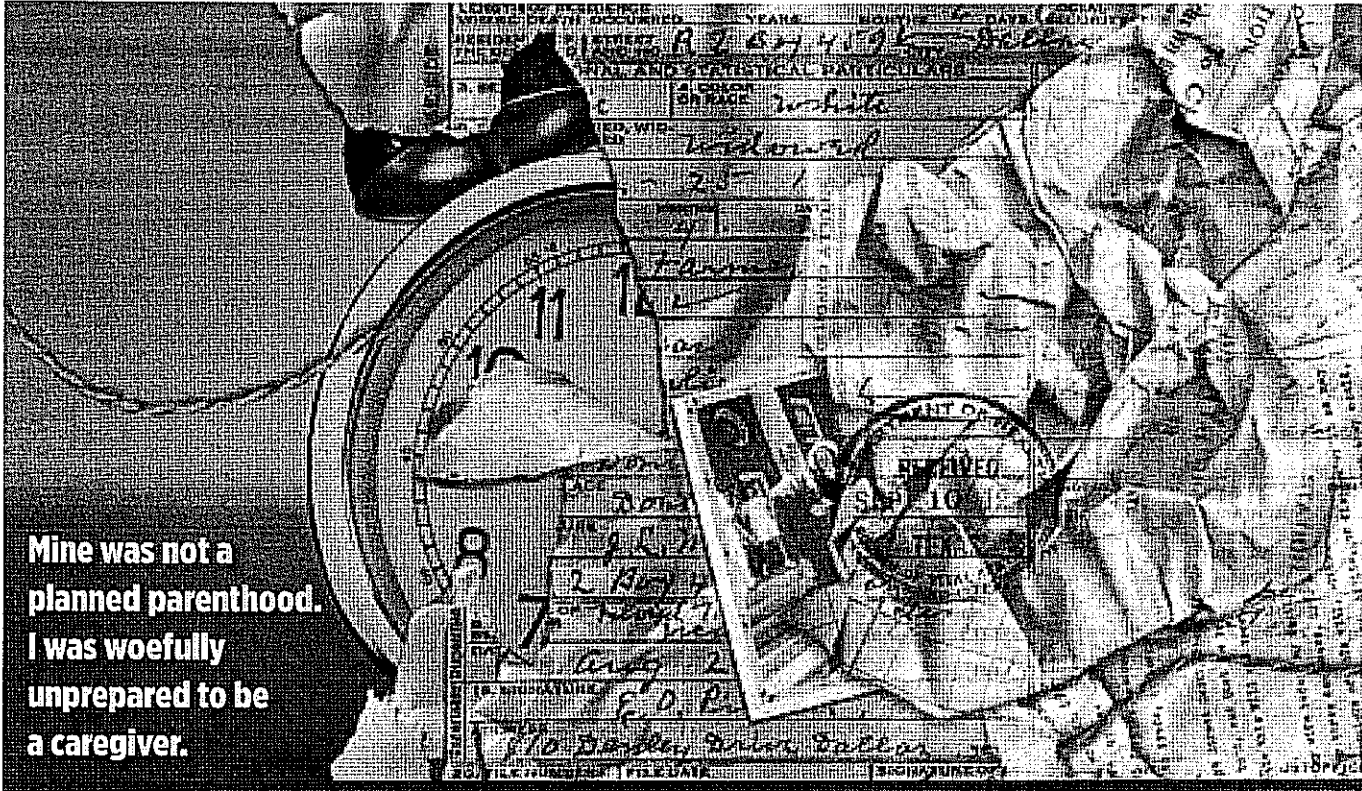
Two days later I flew to Austin and inspected four rehabilitation centers in one day. I chose St. David's Rehabilitation for a very logical reason: A nurse smiled at me. I needed a smile badly that week. They told me that they'd move Dad in an ambulance the following Monday. Then

the question was what to do with Mother.

Two cousins lived in Georgetown and guaranteed their eventual sainthood by volunteering to keep Mom while I reconstructed my life. First I had to get her there. Mother announced in her sweetest Southern belle style: "Jim, I'm not leaving Dallas." She could no longer live alone but was unaware of that fact.

For the first time, I packed for my mother. More accurately, I transferred the contents of her closet into the trunk of their Buick. Monday morning brought the real challenge—getting her into the car. That led to the first of many therapeutic lies. As Mother sipped her coffee, I said, "Would you like to get some ice cream?" Mother never turned down ice cream—not even at 8:30 in the morning. She smiled, put down her cup and happily got into the car. We drove away from





Mine was not a planned parenthood. I was woefully unprepared to be a caregiver.

Concerns That *Need* To Be Addressed

With time, patience and persistence, you are likely to get the information you need—whether it takes one talk with your parents or 10. Be sure to have an understanding of these key issues:

Do your parents have wills and where are they kept? 7 out of 10 Americans do not have a will. 10 out of 10 are going to die. I know because I Googled it.

Make sure your parents assign durable (financial and legal) and health care powers of attorney. Encourage them to choose a practical, trustworthy sibling to make legal, financial and medical decisions if they are unable to do so. Although the forms are online for free, my cousin, the lawyer, says you should spend \$200 and have an attorney draft it.

Be clear about the difference between Medicare and Medicaid.

- Medicare pays for medical care for seniors and some prescription drugs. It does not pay for long-term care. It will pay for up to 100 days of rehabilitation in a nursing home if the patient is making measurable progress.

- Medicaid pays for nursing home care for those who can't afford the cost. It has strict limitations on income and a \$2,000 limit on total assets, with the exception of a primary residence. Approximately 80 percent of Texas nursing home residents are on Medicaid. Medicaid generally does not pay for assisted living.

Encourage your parents to get long-term care insurance. Only about 8 percent of Americans currently have this coverage. Applying before health problems arise will mean lower monthly rates and less risk of being turned down due to pre-existing conditions.

As tactfully as possible, find out the state of your parents' finances. Many of their decisions—and those of their caregivers—will be a direct result of what they can afford. The average cost of a semiprivate room in a skilled nursing home in Texas is \$5,000 to \$7,000 a month. That's \$60,000 to \$84,000 a year and varies greatly depending on their location (metropolitan areas are costlier than small towns), amenities, and the condition and reputation of the home.

Assisted living facilities do not provide nursing care. They offer assistance with the tasks of daily living (taking medications, getting dressed, toileting) and are almost completely private pay. Costs range from \$2,200 a month to \$6,000 and up, depending on the number of individual services provided, as well as location and amenities.

End-of-life decisions: the questions we don't want to ask, but must.

- What are your parents' wishes if they have a condition that is terminal or irreversible? Do they want life support (respirators, feeding tubes) continued indefinitely? A living will (directive to physicians) is necessary to make their preferences a binding legal document.

- Finally, do they want cremation or burial, funeral or memorial service? When I got the nerve to talk to my dad about his funeral, he said, "Jim, do what you want to do. I won't be there. Funerals are for the living."

There are 2.7 million Texans serving as unpaid family caregivers. You might be one of them. The ones who get through this journey with sanity and health intact are the ones who are willing to ask for help.

Don't try to do it all yourself. Reach out to others and accept assistance and support gratefully. In addition to family, friends, neighbors, church and social groups, there are many governmental and private agencies that provide information, advice, referrals and services—usually at no cost.

Eight Suggestions on Having the Talk I *Never* Had:

1. Meet with your parents on a quiet weekend, not during a holiday or family celebration. If it must be at Christmas, make it a day or two after Santa has departed.
2. Prepare well for this meeting. Find out which among the siblings are going to be active caregivers, who will send money but not show up often and who will be missing in action.
3. Don't shy away from asking the tough questions and have someone take notes or record the conversation.
4. Ask what is most important to your parents as they age. Find out what they want and don't want.
5. Listen more than you talk.
6. Give them the respect and dignity they deserve, even if you disagree with their plans—or lack of them.
7. Depending on the state of their health, don't try to make big decisions in the first meeting. This talk should begin an ongoing conversation.
8. Congratulate yourself for getting the subject on the table, no matter how the conversation goes.

her home of more than three decades, and she never saw it again.

True to my word, I stopped at the first Dairy Queen we came to and bought her the biggest, gooiest chocolate sundae imaginable, but somewhere around Waco she must have realized we were going on a longer ride. When we got to my cousins' house, I kissed her goodbye, headed for the airport and jumped on a plane for LA. My body went back to work the next day, but my mind remained in Texas.

Two weeks later I returned to Austin to check on Dad's progress. There wasn't any. This fiercely independent man had flown 75 World War II combat missions in a B-17. Although he was tethered to

tubes, his mind was sharp, and he knew what he wanted. When I walked in his room, he gathered his strength and forced out three words: "Get ... me ... pills." He wasn't talking about aspirin. He wanted me to help him kill himself. As he was nearly deaf, I had to yell my response.

"Dad, I can't do that, I'll go to jail! ... Not hell, Dad, jail! ... Well, maybe hell, too! I can't do it."

He was not pleased with my response. Later that day, one of his doctors suggested a prostate operation that might restore his bodily functions. It worked, and within two weeks Dad was using the restroom unassisted. That's when he

decided he wanted to live.

For six months, I flew to Texas almost every other weekend and finally realized that I couldn't do what needed to be done from 1,000 miles away. I had to make a choice: move my folks to California where they knew no one but me and things were much more expensive, or quit my job and move back to Texas where I had not lived in 30 years. I chose to parent my parents and never regretted it. However, mine was not a planned parenthood. I was woefully unprepared to be a caregiver.

If you remember nothing else from this article, let it be this: Talk to your family about the issues of aging before there is a crisis. Procrastination is your enemy. There will never be a perfect moment to bring up the subject. If all else fails, remind yourself that there are no meaningful discussions on a respirator.

Fear keeps many intelligent, caring families from having this necessary discussion. For parents, major changes late in life are understandably difficult. It may mean selling their home, downsizing, moving in with a child or living in a retirement community. It takes courage to face the realities of aging with wisdom and grace.

Adult children have fears of their own. Many don't speak up to "spare" their parents' feelings when they really want to spare themselves a difficult discussion. They tell themselves—often mistakenly—that a candid conversation will lead to crying, yelling or angry feelings. That may happen in some families, but crying and yelling are far better than not having the information you need when that call comes at 7 a.m.

Jim Comer, author of *When Roles Reverse*, speaks on caregiving to audiences across America. His website is parenting-your-parents.com.

Tape *This* to Your Refrigerator.

These are links to agencies that provide detailed information on programs, services and information that are invaluable to seniors and their caregivers.

The TEXAS DEPARTMENT OF AGING AND DISABILITY SERVICES is a great resource.

Area Agencies on Aging: 1-800-252-9240; dads.state.tx.us/contact/aaa.cfm

Overview of State Services: 1-800-252-9240; dads.state.tx.us/services/caregiver.html

Respite Care: (512) 275-9309; dads.state.tx.us/taketimetexas/about/availableservices.html

Fact Sheet: dads.state.tx.us/taketimetexas/help/respitefactsheet.pdf

Contact Numbers by County: dads.state.tx.us/contact/DADSServicesByCounty.html

Frequently Asked Questions: dads.state.tx.us/services/faqs-fact/index.html

ALZHEIMER'S ASSOCIATION:

National Alzheimer's Association: (312) 335-8700; alz.org

Capital of Texas Chapter: (512) 241-0420; alz.org/texascapital

LEGAL HOTLINE FOR TEXANS: 1-800-622-2520; tlsc.org

This information is also available as a PDF on TexasCoopPower.com.