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Your Guide
to the
NEW BERMUDA

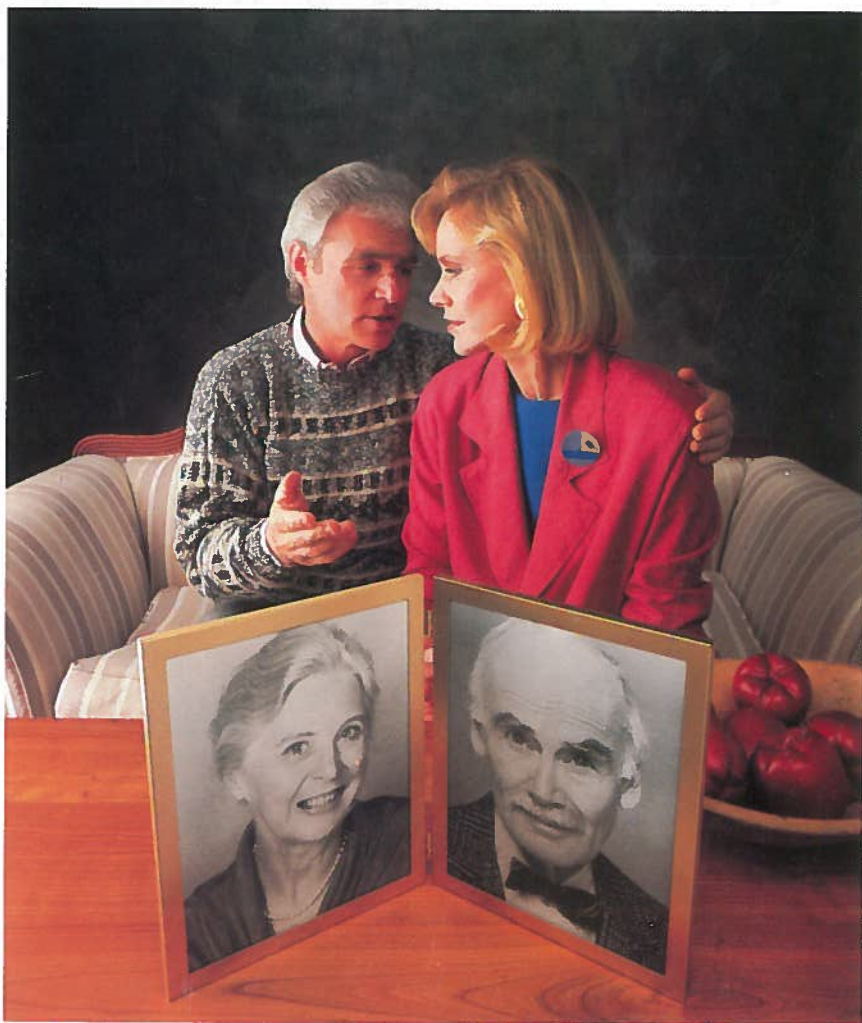
Boston

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Taking Care of Mom and Dad

You know you're an adult when your parents need you more than you need them. It's the hardest part of growing up.



taking care of MOM & DAD

With the graying of America, we can expect to be responsible for our parents longer than for our children. Call it the caring trap.

BY SUE HERTZ

JAMES SILVA SLEEPS A LOT THESE DAYS. BUT WHEN HE'S up, there's no telling what he'll do. Sometimes he'll carry boiling water around the apartment, forgetting that his three small grandchildren may be underfoot. Sometimes he'll carve imaginary chickens with butcher knives. And sometimes he'll escape, slipping out the back door and onto the Brockton streets, walking aimlessly until the police haul him home or someone else finds him. Once his son, Ken, found him wandering through the Combat Zone.

Now there's a gate in front of his bedroom door that locks from the outside. That lock was Barbara Silva's idea. She was going crazy chasing her father-in-law around. But she knows that the lock is merely a Band-Aid. As Alzheimer's disease creeps deeper into his brain, 75-year-old Grandpa James understands less, functions less. At night Barbara Silva puts him to bed. In the morning she cleans up the urine puddles he leaves when he misses the toilet. During the day she shoos him away from the stove, the knives, the china, anything that he could hurt or that could hurt him.

The Silvas know they can't go on like this. One of them will shatter soon, most likely Barbara. But clear solutions elude them. As executors of James Silva's estate, they could

use Grandpa's money for a down payment on that big yellow house three miles from their apartment. Then the kids would have a backyard; Grandpa would have a home; Barbara and Ken would have some privacy. But the mortgage would swallow their checkbook. Day care would end for Elizabeth, 3, and Michael, 5, as well as for Grandpa, who attends the Milton Adult Day Health Center three days a week.

Even in a big house, managing Grandpa as well as Elizabeth, Michael, and David, 7, would drive Barbara crazy. Outside help would be great—if she could get some. Professional homemakers are scarce, and they cost \$12 or more an hour anyway. Barbara could go back to work as a preschool teacher, but then she would have to pay for more day care and for transportation. She would actually lose money.

Nursing homes appall them. "Too many drugs," Ken says. And, "They tie wanderers in chairs." The Silvas fear that placing Grandpa in a home would jeopardize not only his health but also their family's future. If they spend Grandpa's money on a nursing home and not on a down payment on their own house, they will be back to square one. "We're squeezed dry," says Ken.

Barbara, Ken, and the children want Grandpa home but

PHOTOGRAPHS BY SARAH PUTNAM

For the first time in history, we overlap 50 years with our parents' lives. Which means that we can expect to be responsible for our parents longer (18 years) than for our children (17 years).

they can't prolong the decision. The real estate agent is itchy. The lawyer is itchy. Grandpa is getting worse. Barbara shuts her eyes so she won't cry.

"You want to care for someone," she says, "but all the cards are stacked against you."

CARING FOR A DEPENDENT PARENT HAS NEVER BEEN easy, but it has never been this tough. Forty years ago, James Silva might not have lived to be 75, but today, with medical advances, he and his peers are living longer and longer. Today, 13.4 percent of Massachusetts residents—783,000 persons—are elderly (65 or over). Nationwide, 29 million persons, or 12 percent of the population, are 65 and over, and it is estimated that if one reaches 65 (which four out of five persons do), one has a 50 percent chance of living past 80. And although people are staying healthier longer, there is no escaping the fact that by 80 the body wears down and dependency begins. For the first time in history, says Pamela Larson of the National Association of Area Agencies on Aging, we overlap 50 years with our parents' lives and 20 with our grandparents' lives. Which means, she says, that we can expect to be responsible for our parents longer (18 years) than for our children (17 years).

And our changing lifestyles are making it increasingly difficult to be responsible for anybody. Women have traditionally cared for dependent relatives, but as more women enter the work force there are fewer at home to medicate Grandmother or shuttle Grandfather to the dentist. And while men are quick to write a check or fix a faucet for a frail relative, 72 percent of the nation's care givers are women, half of whom also work outside the home.

Mobility, delayed parenting, and economics complicate matters. Families don't live just around the corner anymore but often hundreds or thousands of miles away. One generation may have to uproot itself when the elderly require care. And as adult children pursue careers, they often have children later in life, which means that these adults are sandwiched between the needs of two generations. A spouse could quit his or her job to provide the care, but losing that income could be devastating in today's marketplace, particularly in the Boston area, where it usually takes two salaries to pay for a condominium.

"The stress," says Barbara Silva.

"The stress" is right. A stress that neither the family nor the government nor the community is prepared to face.

IN THEIR WORST NIGHTMARES THE SILVAS DIDN'T ENVISION finding themselves in this jam. They were doing so well before Grandpa arrived from San Diego, in April 1986. They were saving money from Ken's new job as a construction foreman and from Barbara's teaching; a new house looked possible. When Grandpa moved in, however, they decided to wait to see how much supervision he needed before they assumed a mortgage.

Barbara, 35, is small and chatty, with porcelain skin and a childlike air. Ken, 45, is more than six feet tall, dark,

brusque, and animated. At first, Ken stayed home to chase Grandpa when he sneaked out. Sometimes he would find him two blocks away. Sometimes he would find him in nearby Rockland. When Ken returned to work, in September, Barbara quit teaching preschool and took over. Day after day, she felt like a cop as she stalked Ken's wandering father through Brockton.

In their five-room apartment, James was everywhere. When he wasn't in the kitchen slicing pictures out of magazines with a knife, he was in the bedroom changing clothes. Most of the time he paced. Back and forth, from the living room to the kitchen. Adult day care three times a week provided some relief, but not enough to free Barbara to teach or resume the classes at Bridgewater State College that would lead to a degree and a better job. Ken and Barbara watched their savings shrivel as they shelled out thousands of dollars for day care, transportation, and insurance—which was formerly covered by Barbara's teaching job.

Less than two years after Grandpa moved in, their money is almost gone, as are their options. Ken votes to move. "The worst that could happen is we live in a big house for a year," he says. Barbara shoots him a look. That's not the worst. If they use Grandpa's money for a down payment, the deed will be in his name, the house his. If he deteriorates to the point that he requires institutional care, Medicaid, the federal and state service that provides assistance for low-income and disabled people, will assume the cost. When a Medicaid recipient dies, however, the state is entitled to reimbursement and could claim his or her estate. Which means that Barbara and Ken could lose the house and all the money they put into it.

Barbara looks around her tiny kitchen and thinks of the past weekend, when all six of them were locked inside. Grandpa paced. Cartoons blasted on the television. She and Ken slept on the mattress in the dining room. She can't go another month.

BARBARA SILVA'S PLIGHT MAKES JANICE GIBEAU SHIVER. For the past few years, Gibeau, director of the Franklin County Homecare Corporation, has studied women across the country who are caught between care giving and breadwinning. She knows that as the number of frail elderly soars, so will the number of women in the labor force. By the turn of the century 75 percent of women between 46 and 60—the primary years for caring for elderly parents—will work outside the home.

The conflict is disastrous. Most of the women Gibeau interviewed said they struggled, missing an average of 35 hours, or one week's work, a year to run errands, settle parents in the hospital, oversee medication. That's not counting the office hours spent telephoning health-care agencies or the time wasted fretting. The result can be poor job evaluations, limited promotions, and minimal salary raises. Gibeau fears that more women will quit their jobs as Barbara did to tend an elderly relative, thereby creating a new "generation of impoverished women." To lose health benefits, retirement benefits, and job advancement is to mortgage their



Psychologist Carol Golub, right, knows that her mother, Blanche Gustafson, is lonely in her nursing home (above). Says Gustafson: "I'm ashamed. I sometimes cry because I depend on her so much and she's so busy."

future. A study by Elaine Brody, director of the Philadelphia Geriatric Center, fuels her fears. Twelve percent of the working women interviewed by Brody had quit work to care for an aging relative, and 26 percent said that they had considered quitting. "To keep someone they love from being at risk, they sacrifice themselves," says Gibeau.

To be fair, women like Sophie Eldridge can't see the future when the present is so consuming. Eldridge doesn't like to think about her job performance at Wang Laboratories in Lowell. For the past year she has had too many other things on her mind to worry about her phone calls from Wang to the Medicaid office or the days she missed running back and forth to Falmouth, where her parents have suffered yet another catastrophe.

Eldridge is 35, with big brown eyes and streaks of gray through her dark hair. She says that she would like to use

her real name, but her parents would be crushed if they read of her fatigue and frustration. She dawdles over a lunchtime salad, claiming that she's too drained to head back to work. And besides, she needs to talk; few will listen to her story.

She used to work hard, took pride in her rise from switchboard operator to engineering coordinator. But since Christmas 1986 she has had little energy left for her 9-year-old daughter and fiancé, let alone for her job. First, her mother, already crippled by arthritis, suffered three grand mal seizures on Christmas Eve. Two months later her father, who suffers from Parkinson's disease, contracted diverticulitis, an intestinal inflammation. Her mother, stiff and weak, could barely open a soup can. Her father required help to bathe and dress and shave. Eating a sandwich took him half an hour. With a sister in California and a brother in western (Continued on page 178)

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MOM & DAD

(Continued from page 135)

Massachusetts, Sophie Eldridge, in Dracut, was the closest, so she began her weekly two-hour commutes down to the Cape to clean gutters, hang laundry, buy groceries.

"No one said I had to," she says. "I assume responsibility for the love I feel for them."

She describes her mother as a giver, the good Christian who cared for anyone who was hurting, and her father as an easygoing man who, when she rammed his car into the display window of his photo shop when she was 16, simply said, "Back 'er out." But even Eldridge's love and respect are tested as her mother, frustrated by her handicap and dependency, grows more demanding, and her father's needs increase. She bathes and shaves him, cuts his toenails. Soon, she knows, he'll be incontinent. She tried to hire someone to ease the household tasks,

Eldridge figures that she has missed a full week's work by taking days off here and there to settle her parents into or out of the hospital. The first time, her boss understood. The next time, he docked her vacation days. Now he says that her family takes advantage of her and warns her that she can't take more time off.

but her mother, a private person, couldn't stand to have a stranger straighten her closets and dust her bureau.

Fortunately, Eldridge was among 37 Wang employees selected to participate in a project sponsored by Wang, the federal Administration on Aging, and the Elder Services of the Merrimack Valley, which pays for adult day care close to the parents' home. Her father loves it, but Eldridge knows that at \$25 a day the respite will last only as long as Wang pays for it. She has suggested to her parents that they sell their house and move to a retirement community. Her parents won't budge. Even though they haven't walked the beach in three years, they love the Cape.

Eldridge calls her parents at least once a day, usually from home, but admits that much of her workday is consumed by worry and phone calls to elder-service agencies. She figures that she has missed a full week's work by taking days off here and there to settle her parents into or out of the hospital. The first time, her boss understood. The

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next time, he docked her vacation days. Now he says that her family takes advantage of her and warns her that she can't take more time off. But last May, when Eldridge thought she suffered from asthma, and her doctor said her problem was stress, she was ordered to stay home for two weeks.

She knows she won't get promoted, but she doesn't care. "I have a lot on my mind, and my job isn't my top priority," she says.

IN A WAY SOPHIE ELDRIDGE IS LUCKY: outside services were available. For many, finding assistance can prove as taxing as care giving. Demand far outweighs supply.

Like other service industries in which wages hover around \$6 an hour, home health care suffers a critical staffing shortage, especially in areas of low unemployment, such as Massachusetts. When Ken Charest of Wakefield sought a worker from Mystic Valley Elder Services to vacuum and scrub his parents' home, he hired a young woman who barely dusted around the lamps before she plopped down to watch TV with his 82-year-old father. Charest thought of asking for a replacement but feared the next helper would be worse.

Ten years ago, Home Health Visiting Nurse Services of Northern Essex, in Haverhill, would receive 50 responses to a newspaper ad for a homemaker—someone to do light housekeeping, shopping, or cooking. Now, if the nonprofit outfit runs an ad for a week in three newspapers, it's lucky to get 10 responses. The staff receives bonuses for bringing in reliable help.

State agencies don't fare any better. There are 27 home-care corporations in Massachusetts that assess elderly needs and then contract services with private agencies in the community. To be eligible, the client must have an income of less than \$8,000 (\$11,150 for two) annually, be impaired in two or more daily activities (bathing and dressing, for example), and be without a family member available to provide care. Forty-five thousand older persons in the commonwealth are served through the corporations, but because of the worker shortage, hundreds who have applied and have met every requirement still lack help with everything from buttoning shirts to getting out of bed. Last summer a survey of all 27 home-care corporations showed that 1,700 elderly persons for whom help had been authorized had yet to see a homemaker.

Albert Norman, executive director of the Massachusetts Association of Home Care Programs, says that the association's average case manager carries 73 clients, which means the manager has 45 minutes a month per client to assess the situation, come up with a plan, and make a follow-up visit. To come close to providing care for all eligible applicants, according to Norman, the case limit should be 55 clients for each manager. "Wage is low, status is low," Norman says.

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MOM & DAD

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Complicating matters is the Prospective Payment System, a four-year-old federal plan that reimburses hospitals for Medicare patients' care based on average costs for a particular diagnosis. There are 471 Diagnosis Related Groups, or DRGs, ranging from cataract to coronary bypass surgeries. Designed to limit health costs, the system, overall, has cut the length of hospital stays. Consequently, many elderly require more home service. But there are too few care givers to provide it.

Both home health aides, who are trained to provide personal care under the supervision of a registered nurse or doctor, and visiting nurses are in short supply. It is estimated that 25 percent more home health aides are needed to meet the state's demand. Similarly, visiting nurses are stretched beyond their limits. For example, last year 120 nurses from the Visiting Nurse Association of Boston made 254,000 visits. In 1970, 120 nurses made 125,355 visits.

Families can hire help privately, but, as Barbara Silva found, hourly wages start at \$12. Adult-day-care centers are an option, but there are only 1,200 centers for the 29 million 65-and-overs nationwide. Massachusetts residents are fortunate: for the 1 million plus 60-and-overs in the state, there are 48 social centers for the self-sufficient and 80 adult-day-care centers for frailer seniors who require medical attention. Even so, unless the family qualifies for public assistance, the fees—which range from \$25 to \$50 a day—can be prohibitive.

There is hope. Little by little, state funding has increased. The state home-care program's budget went from \$100 million to \$113 million between 1986 and 1987, and to \$125 million for 1988. Still, says Albert Norman of the Association of Home Care Programs, "For every \$1 spent on home care, the state spends \$5 on institutional care."

CONTRARY TO MYTH, FEW FAMILIES want to place their parents in retirement homes. While there are 55,000 nursing- and rest-home beds in the state, more than 80 percent of elder care is provided by relatives, a payback for the love and care their elders gave them. "You don't cast someone aside because they're old," says Ken Charest of Wakefield, whose mother has lain in bed for 10 years, since her stroke. But there is a fine line between giving and martyrdom.

For three years, clinician Anne Gillis has offered support groups in Watertown for adult children of aging parents, hoping to provide care givers with a safe place to purge unresolved feelings of guilt and to admit that they feel victimized and overwhelmed, that although they love their parent dearly, the responsibility is too much. "People need to know their own limitations," says Gillis. "They need to take care

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MOM & DAD

of themselves. The responsibility of a parent involves a lot of care giving, and it is unrealistic to think they can do it alone."

Tonight, 11 women sit in a circle in a room at the Center for Mental Health and Retardation Services in Watertown, each asking that her name be withheld to prevent the hurt she knows the publicity would cause her parents. Men don't attend these groups. The closest Gillis came to having a man in her group was when a husband sent his wife to discuss his concerns about his mother.

Sally speaks first. She is 50 and has never lived apart from her mother. That may seem unusual now, Sally says, but when she was young, women didn't leave home until they were married. When Sally was young, she just never met a man who seemed right, and as she grew older her mother quashed every prospect. Sally sought guidance from a psychiatrist but dropped him when he told her to move out of the apartment. Her mother is 82, she says, and unable to live alone. "I can't leave her."

Ellen says she feels like the "slave of the week" now that she's living with her 91-year-old father, shaving him, medicating him, chauffeuring him. And all he does is complain. When he dies she'll get her hair cut and maybe go out on a date.

Mourning? She has been in mourning for years.

Kay and her husband are in troubled financial straits. When her father died, two years ago, she was happy that she could offer her mother, who is 66 and suffers from Parkinson's disease, a place to live. Kay and her husband hoped that the sale of her mother's house would help them with the cost of adding another person to their household. But her mother has refused to sell, and Kay and her husband must shoulder the taxes, insurance, and utilities on her home. "She felt we wanted to deprive her of her house," says Kay.

"When the elderly are faced with change, they become defensive, angry at anything that threatens their loss of control," says Gillis.

"The elderly can't give up the control that remains to them," adds Vicky, who has cared for her 89-year-old father for more years than she cares to count. "So much has been taken away physically. All that's left is what they own."

"Get a good lawyer," says Allison.

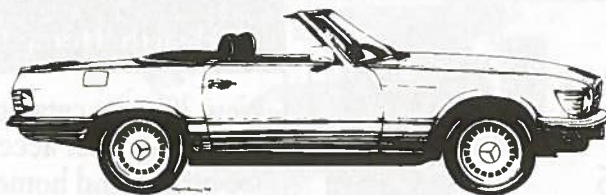
Allison is angry. She has been divorced for 16 years. She has a teenage son and says that her family has left the details of her mother's care to her. Although her mother, age 86, has lived in a Vermont convalescent center for years, she refuses to sell the family home, in White River Junction. She accuses Allison of "changing things around" and argues that someday she'll move back. Allison would like to transform the house into a ski lodge or a vacation rental, something fun that would make money, but she can't with good conscience. Weary of the

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commute from her Charlestown home to Vermont, she thought of quitting her job and moving into her mother's house, but then she wouldn't be able to afford to send her son to college.

"I'm ambushed by sadness," Allison tells the group. "I cry all the way home. I know every rest area on [Interstates] 89 and 93." Part of her is sad for her mother. Part of her is sad for herself. "I see myself there."

"It's not that far away," says Ellen.

They rise to say good-bye, each feeling a little better because they know that no matter how desperate they feel, there is always someone worse off than they.

TO THE OUTSIDER, CAROL GOLUB IS IN an enviable position. A psychologist with both a private and a clinical practice, Golub, 46, lives in a modern house nestled in six acres of Boxford woods with her own lap pool. Her hours are long but flexible, and somehow either she or her husband, Herbert, who is also a psychologist, is home to help the couple's 15-year-old son, Steven, with his homework in the afternoon. Steven is learning disabled and almost totally deaf.

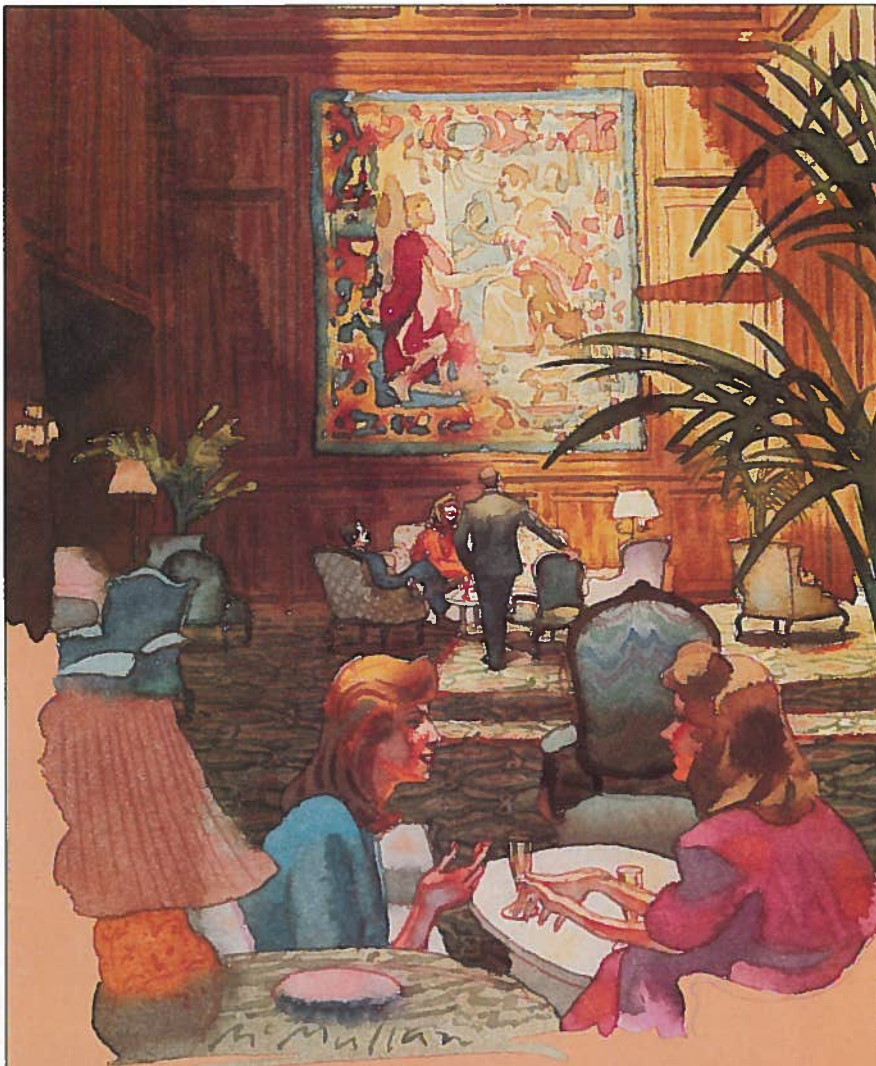
When Golub's mother, Blanche Gustafson, moved east from her Minnesota home, almost four years ago, they thought they would function as always; they would just be a bit busier. But from the start, Gustafson, then 80, was miserable. Accustomed to her own apartment and friends, she was desperately lonely at the Carlton Home, in Georgetown. With her eyesight failing and her heart too weak to allow her to walk much, she would call her daughter daily asking how she should spend her day. The other residents of the Carlton Home, which offers supervision but no medical care, kept to themselves. Golub spent much of her week driving between Boxford, Georgetown, and her clinic, in Wilmington. Often she brought her mother home, attempting to entertain her, prepare dinner, make business calls, and help Steven. She folded laundry at midnight, after she saw her last client.

She thought the schedule would ease last fall, when they moved her mother to the Prescott House, in North Andover. Elegant, with royal blue carpeting and linen tablecloths, the nursing home keeps residents busy with cocktail parties, sing-alongs, and outings to Pickering Wharf, in Salem. But her mother has yet to adjust.

Day after day, night after night, Golub answers the phone to hear her mother sobbing on the other end. She lost her hearing aid; she misses her relatives in Minnesota; can Carol visit tomorrow?

Gustafson says from her nursing home: "I'm ashamed. I sometimes cry because I depend on her so much and she's so busy." Golub says, "I learned from my mother that you give to everyone." But, she adds, "I don't know if I can do it for as long as I'll have to."

Golub exudes an inner strength that oth-



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ers can lean on. That's a quality that makes her a good psychologist. But her husband would like more time with her, and she'd like some time, even an hour a week, for herself. "Sometimes I feel like I'm looking in my pockets and under my arm when I see a client," she says. "What can I give this person?"

THERE ARE NO EASY ANSWERS FOR those people caught in the caring trap, although solutions are being sought—on the corporate level, at least. Across the nation, businesses are studying the conflict of care giving and work and realizing that this is *the* issue of the nineties. Travelers Insurance Company, based in Hartford, is the leader of the movement.

After conducting a survey in 1985 and finding that 20 percent of all its office employees age 30 and over care for an aging relative, Travelers instituted lunchtime seminars on coping, weekly support groups, referral services, and care-giving fairs. Other corporations have followed suit, including three Connecticut-based companies that work with the University of Bridgeport to explore increased flextime, various benefit packages (which would include dependent relatives), lunchtime support groups, and resource referrals. Last June, more than 300 representatives from 70 corporations attended a seminar in New York City on issues of employees and elder care. Locally, there is Wang's day-care program and an elder-care consultation-and-referral service provided by IBM for its employees in Greater Boston. To awaken more Boston businesses to the crisis, the Health Action Forum is hosting a four-part seminar this winter and spring on employees and elder care.

Yet we're not moving fast enough. By 2030, 65 million baby boomers will be elderly. More than 75 percent of our daughters will be in the work force. Experts like Janice Gibeau see some solutions in flexible work hours, job sharing, on-site adult day care, and benefit packages that include long-term care. But more action is needed. "We're a 'now' generation," says Gibeau. "We don't believe the road is going to go until it collapses."

Women like Barbara Silva can only hope that their daughters will have more help than Silva has found. Perhaps by that time sons will have assumed equal responsibility. But without more day care, more home health aides, and affordable nursing homes, it won't matter.

In the meantime there are decisions to be made. Grandpa has wakened from his afternoon nap. A benign-looking man with a sal-low complexion and vacant look, he carries a cup of coffee across the kitchen.

"I've got it," says Ken, reaching for the cup.

"I've got it," says Grandpa.

Barbara shrugs. No one's got it. □

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