

Don't hesitate to get help with a dementia patient

Do it sooner than later, experts say

By Mary Brophy Marcus
USA TODAY

Marilyn Blum is like a lot of wives with a retired husband around the house. She loves the man she has been married to for 33 years but says, "It's just not normal to be together 24/7."

Blum's comment is more poignant when she explains that her husband, Steve, 65, has had Alzheimer's disease for five years and needs help dressing, grooming, eating and using the toilet.

"I wish I had gotten paid help right away. I waited two years," says Blum, 61, of Owings Mills, Md.

Now Steve participates in an adult day care program. A paid companion, Evadne Cummins, visits the house three times a week to keep Steve company, make lunch, go on walks and help with basic grooming.

Like the Blums, about 70% of families coping with Alzheimer's and other dementia have loved ones who live at home, the Alzheimer's Association says.

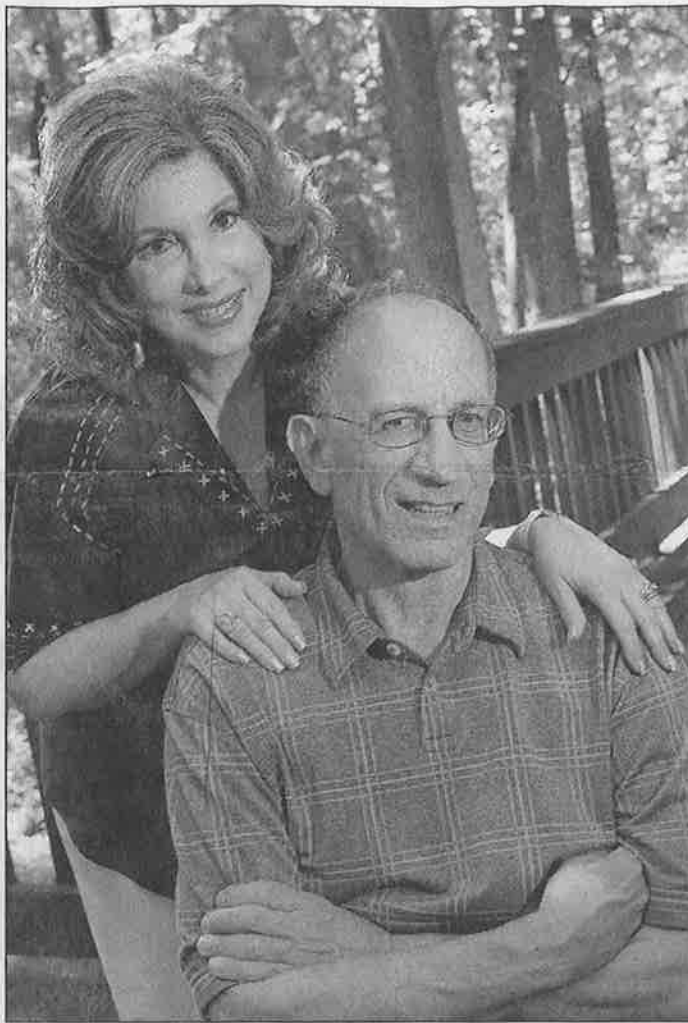
Most of those families do not have any assistance from paid health workers; family members and friends do all the care.

This week, a study will be reported from the annual Alzheimer's Association International Conference on Alzheimer's Disease meeting in Honolulu on the influence of diagnosis and care management on health care costs.

Experts say having no outside help can take a toll on caregivers and patients alike.

Cost, finding care you trust and not knowing resources are roadblocks to getting paid help, says nurse practitioner Brigid Reynolds, clinical coordinator at the Memory Disorders Program at Georgetown University Medical Center in Washington, D.C.

The options range from a few hours of companionship a week early on to part-time local senior center Alzheimer's day care to full-time nursing home or in-home assistance in the final days, she says.



Together for 33 years: Marilyn Blum and her husband, Steve, 65, who is in the middle stages of Alzheimer's, at home in Owings Mills, Md.

The earlier you create a care plan, the better, Reynolds says.

But she and other Alzheimer's experts say many families don't plan enough: "The inaction is sort of an inability to grasp onto and realize this is a terminal disease."

Guilt can get in the way, too, says Gary Kennedy of the Division of Geriatric Psychiatry at Montefiore Medical Center in the Bronx.

"Guilt is automatic for family caregivers. Families feel connected and responsible," says Kennedy, who suggests families start paid care in small increments, maybe a few hours a week.

Sometimes patients will fight an outside caregiver, though.

Carol and Bob Blackwell hired full-time, in-home care for Bob's mother when she was in mid-stage Alzheimer's. (Bob, who has Alzheimer's, blogs for USA TODAY

at alzhimers.usatoday.com.)

"That lasted two days because she woke up in the night once, got confused about the new caregiver, chased her around the house with a broom, called a taxi and took off," Carol Blackwell says.

But it's worth trying different people to find the right chemistry, says Blum, who tried a few day care centers and companions before finding a fit.

She spends her time off doing advocacy work for the Alzheimer's Association, running errands and catching up with friends, and says she's happier for it.

"Unfortunately, the pattern seems to be what I did: waiting till you're so worn down that you're pretty desperate," Blum says.

"This can be a long process. The caregiver has to preserve their own strength."

Alzheimer's patients' options for paid care

Many families try to provide all the care by themselves, but paid help can be a valuable option, says Beth Kallmyer, senior director of constituent services at the Alzheimer's Association. "The earlier you make a plan, the better," she says.

The range of services and costs vary. Some types of care:

In-home care

What is it? Basically, companion services provide supervision, social engagement and some light household help.

Qualifications: Non-medical person, home-care aid or nursing student. Ask for and check references.

When needed: Moderate- to late-stage Alzheimer's. Patients in earlier stages would benefit from more social stimulation.

Cost: About \$19 an hour.

Home health care

What is it? Provided by a licensed health worker — a nurse, social worker or occupational therapist. Nurses can give medicine. Focus is generally on medical issues.

Qualifications: At least a bachelor's of science degree in nursing or other health-related field.

When needed: Typically hired if Alzheimer's patient requires short-term medical care, for example, care after surgery.

Cost: Often covered under insurance, but only for an acute illness or condition, not Alzheimer's-specific help.

Adult day care center

What is it? May be an adjunct to a senior center, YMCA or a Catholic Charities program. Sometimes privately run. Social outlet outside of home that offers daily routine.

Qualifications: Depending on program, staff can include nurses, social workers, certified nursing assistants or non-degreed, trained workers.

When needed: Early- to late-stage Alzheimer's.

Cost: An average of \$67 a day.

Full-time assisted living

What is it? Patient lives in an apartment-like setting, semi-independently among other seniors, where meals and some other services are provided. Healthy spouses can live together.

Qualifications: Trained workers, nurses, some certified nursing assistants, social workers, therapists.

When needed: Early- to midstage Alzheimer's.

Cost: About \$52,000 a year.

Nursing home

What is it? Full-time medical care in an institutional setting. All medical and personal needs are met by trained staff.

Qualifications: Staffed by certified nursing assistants, medical technicians, social workers, therapists, nurses and doctors. Sometimes hospice workers.

When needed: When issues including wandering, behavioral problems and incontinence arise.

Cost: More than \$75,000 a year or more.

Sources: Alzheimer's Association; Murali Doraiswamy, Duke; Carolina Rodriguez, UCLA; Brigid Reynolds, Georgetown