

RETIRING | SUSAN B. GARLAND

Financial Resources to Cope With Chronic Illness

After a life-changing diagnosis, start building a team to help handle long-term expenses.

WHEN FRED SCHWARTZ was diagnosed with multiple sclerosis in 1994, the financial challenges that lay ahead were not top of mind.

“My health was my main concern,” Mr. Schwartz said. “I didn’t know what was going to happen.”

But the costs of his chronic illness began to loom large eight years later when Mr. Schwartz, 52, left his job as an insurance-reimbursement manager for a nursing-home company. By then, he could no longer use his legs.

In the years since, he has painstakingly pieced together financial aid from numerous sources — for living expenses, caregiving and special equipment — that he anticipates will allow him to live at home for many years.

As the population ages, the numbers of people diagnosed with Parkinson’s disease, heart conditions, Alzheimer’s disease and other chronic illnesses are rising. A diagnosis may be alarming enough, but equally frightening can be the costs for medical treatments, home renovations and other expenses. Some people with disabling conditions may be forced to retire earlier than they had planned, resulting in a loss of income and potential retirement savings.

Dr. Carolyn McClanahan, a physician and certified financial planner in Jacksonville, Fla., said her clients with new diagnoses “have three worries from a financial standpoint. Will I be able to afford to take care of my illness? Will I leave my family devastated?” And, if the sick person runs the family finances, she said, her client will worry “whether the spouse will be able to take over.”

Seek Out Information

One of the first steps is to build a team of professionals, experts say. Besides your doctor, your team could include an elder-law attorney, who could draw up health care and financial directives and plan for Medicaid to pick up the costs of long-term care if assets are depleted, along with a financial adviser who has experience with chronic-illness planning. A geriatric care manager, hired even for just a few hours, could give advice for care, home modifications and other services.

Local community groups geared to older adults could recommend a variety of services, including rental subsidies or housing with amenities for those with disabling conditions. Some programs match older adults with younger roommates who can provide help in exchange for no or low rent.

Another possible source of guidance is an advocacy organization.

At the National Multiple Sclerosis Society, “navigators” field 40,000 inquiries a year, said Karen Mariner, a vice president. The group may connect callers to financial planners with knowledge of the disease, review insurance coverage, and point callers to government agencies and nonprofits that provide free and low-cost services, she said. Mr. Schwartz said the MS Society paid for a roll-in shower for his bathroom.

“If you are new to this, you don’t know where to go,” Ms. Mariner said. “We help individuals understand what they need and how to get the resources.”

For newly diagnosed clients who are employed, Dr. McClanahan said she recommends that they stay on the job if they can. Besides earning income, their health insurance will most likely be better and cheaper than policies on the individual market.

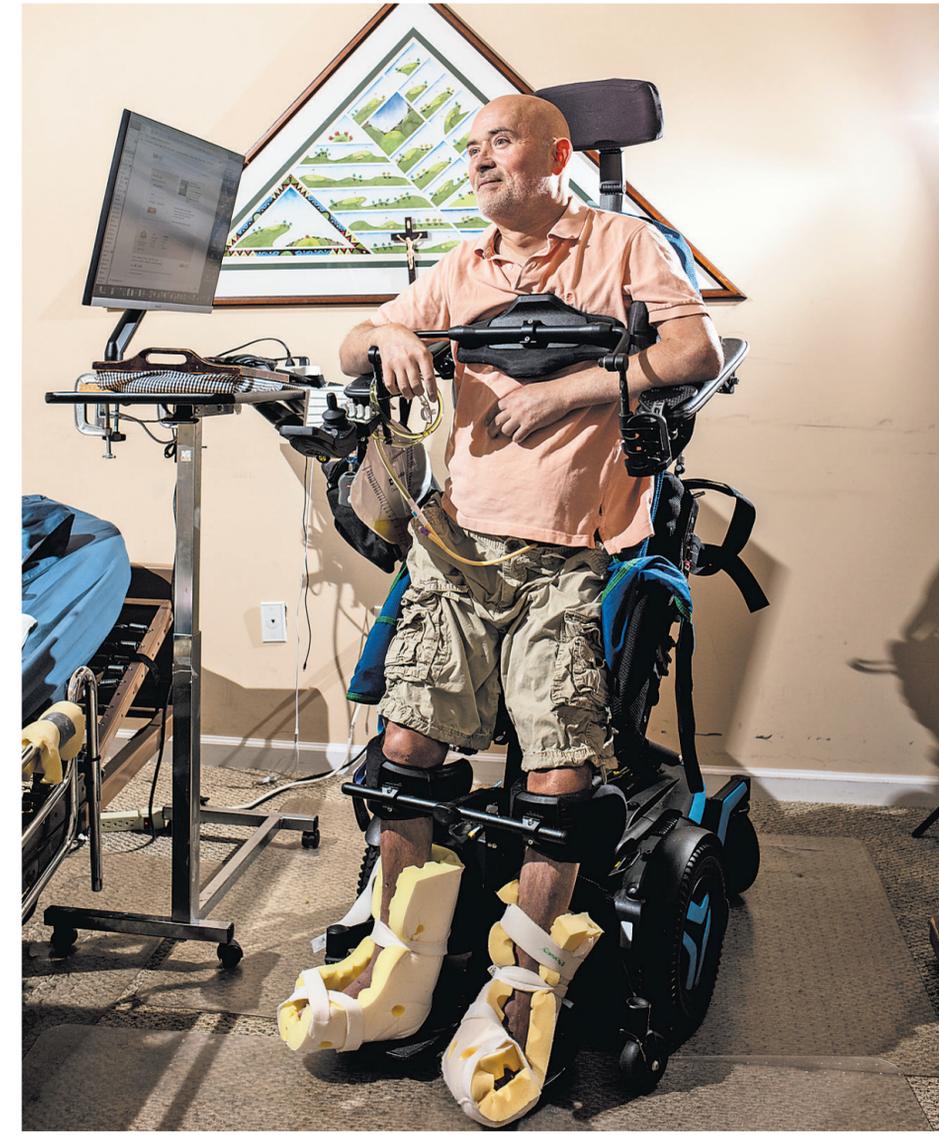
Employees should enroll in group plans for long-term care insurance and enhanced disability coverage as well, she said. Group policies generally do not require medical underwriting.

Assemble a Menu of Assets

When Mr. Schwartz left his job, his doctor helped him file for Social Security Disability Insurance, which pays a benefit to someone who is younger than 65 and can no longer work.

Under the federal COBRA law, he paid premiums to his former employer’s health plan until he qualified for Medicare.

In addition to \$900 in monthly Social Se-



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curity benefits, he receives \$2,000 a month from his former employer’s long-term disability plan, which he said would pay out for his lifetime.

“I was very fortunate to work for a company that had that benefit,” said Mr. Schwartz, who also earns roughly \$700 a month helping an accountant prepare tax returns. “I also have my family.”

Mr. Schwartz’s father, who lives in Arizona, used proceeds from a property sale to build Mr. Schwartz a house in his native New Jersey. They own the house jointly, enabling the son to qualify for a state property tax break for the disabled.

Another piece of the patchwork: a state disability program that pays for more than 30 hours a week for a caregiver. A case manager for the MS Society arranged for the care. The aide prepares meals, drives Mr. Schwartz to medical appointments, and helps him get in and out of bed. The aide and his wife live in the house, rent free.

“He sees me as a father figure,” Mr. Schwartz said. “He is a dear friend.”

For a better picture of future expenses, someone with a new diagnosis should ask about the likely course of the disease, experts say. Life expectancies and the types of care will differ depending on the condition.

With a client’s general prognosis in hand, James Sullivan, a certified public accountant with Fairhaven Wealth Management, in Wheaton, Ill., will draw up a budget for the first 12 to 18 months after a diagnosis.

“The budget begins to incorporate what we anticipate the care needs will be,” he said.

Mr. Sullivan first reviews current expenses and income sources. He may eliminate certain outlays, such as travel, while adding anticipated care-related costs. These may include a home aide or medical devices not covered by insurance.

“I compare it to a wedding,” Mr. Sullivan



said. “There are a thousand little expenses that add up and that Medicare doesn’t cover.”

Additional sources of cash flow could include disability benefits, annuities, home equity loans and tax savings. Some clients, he said, have life insurance with accelerated death benefits, which pay a portion of your benefit while you’re alive.

Mr. Sullivan put his expertise to work when his brother learned he had Alzheimer’s disease in 2018 at age 65. Just before the diagnosis, Richard Sullivan, known as Rick, had retired as senior economist at the Federal Reserve Bank of Kansas City.

“Rick was hoping to travel and have a good time,” said his wife, Leslie, who lives in Prairie Village, Kan. “The money he saved in his retirement account will be used instead for memory care.”

To care for her husband, Ms. Sullivan, 68, retired earlier than she had planned as a project manager at the University of Kansas Medical Center, where she instructed

Fred Schwartz, who has multiple sclerosis, manages financially with public and private help. The MS Society paid for a roll-in shower, and a GoFundMe campaign helped pay for a standing frame for his wheelchair. He works part time preparing tax returns.

‘We will be fine if I don’t buy any more shoes,’ says one retiree’s wife.

medical students on Medicare and other nonmedical issues. “It was unfortunate because I loved my job,” she said.

Her husband had taken care of the finances. Ms. Sullivan consolidated bank and retirement accounts, which made it easier to manage the money. She freed up cash and reduced headaches by selling their four-bedroom house and moving into a two-bedroom apartment.

With her brother-in-law’s help, Ms. Sullivan reviewed the household’s cash flow. She generates more than \$7,000 in monthly income from their Social Security, her husband’s pension and small withdrawals from his retirement account. To save on taxes, she plans to suspend these taxable withdrawals and instead tap a bank account that holds proceeds from the home sale.

The income covers basic expenses and \$225 for three days a week of adult day care. To postpone paying for memory care, Ms. Sullivan said she intended to keep her husband at home as long as possible. Her husband’s retirement funds would pay for roughly eight years of memory care, she said.

Though she tries to pinch pennies, Ms. Sullivan said she lowers the stress of cooking by splurging on prepared meals. “We will be fine if I don’t buy any more shoes,” she said.

Trim Health Care Costs

Drugs can be a huge expense for chronically ill patients. Medicare beneficiaries should comparison-shop for Part D prescription drug plans every year during open enrollment, Dr. McClanahan said. Drug plans may drop medications from their formularies or raise prices.

Some drug manufacturers and nonprofit organizations offer savings programs. Depending on the insurance plan, some patients save money by switching from self-administered drugs to medications administered in a clinical setting.

Before she became eligible for Medicare, Deborah Rosenwinkel, who lives in Wheaton, Ill., and has rheumatoid arthritis, used a manufacturer’s discount card for Enbrel, a biologic she injected at home once a week. The \$12,000 card covered her deductible and co-payments, while her individual insurance policy picked up the balance, of up to \$80,000 a year.

But when Ms. Rosenwinkel turned 65 last February and enrolled in Medicare, she was no longer eligible for the card. Even when a Medicare Part D plan covers Enbrel, annual co-payments could run as much as \$7,000.

Ms. Rosenwinkel’s rheumatologist advised her to switch drugs. Because the new medication is injected monthly in the physician’s office, it falls under Medicare Part B, which covers outpatient services. Medicare and her private Medigap plan cover the total cost.

The price tags for wheelchairs, patient lifts and other durable medical equipment also can be steep. Medicare pays 80 percent if the doctor and supplier are enrolled in the program. Disease-specific organizations or local aging organizations may be able to recommend nonprofit groups that provide free or discounted equipment.

Mr. Schwartz’s wheelchair cost \$30,000, with a \$6,000 co-payment. But Medicare did not cover a standing frame, which improves muscle and bone strength by enabling users to stand with support. To help pay for the \$15,000 device, he raised more than \$10,000 in a GoFundMe campaign.

Another source of financial help: tax write-offs. Taxpayers can deduct medical expenses that exceed 7.5 percent of adjusted gross income. Among eligible costs: drug expenses, home improvements such as support bars, assisted-living charges and medical equipment. To take advantage of the deduction, people who have large medical bills should consider tapping sources of taxable income, such as an individual retirement account, Dr. McClanahan said.

While he deals with his own physical and financial challenges, Mr. Schwartz helps raise money for others with multiple sclerosis. Over 10 years, first for the Myelin Repair Foundation and then for the MS Society, he has made six tandem sky-diving jumps. He hopes to jump again in June.

“People say I am amazing, and it feels good for people to tell you how great you are,” he said.

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