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Consultants Corner

By Ann Stewart



Patient advocacy becoming essential; New Medicare law increases need

By the time she was halfway through her cancer treatment, Marcia Soule had accumulated nearly \$30,000 in debt. She and her husband didn't have health insurance and, according to officials in the hospital where she initially received treatment, her husband earned too much to make the family eligible for assistance from MassHealth. That's the Medicaid program which provides health care benefits to certain low and medium income families living in the state.

Exhausted by her battle with breast cancer, Marcia had just about given up trying to get coverage and had resigned herself to living with debt, which she believed would take many years to pay off.

When I joined Commonwealth Hematology-Oncology (CHO), the only community physician group that has a patient advocacy program, I assumed Marcia's case. I began to advocate on her behalf, and it took me many months of negotiation and documentation to finally convince MassHealth that she was an appropriate candidate for coverage.

CHO created the patient advocacy program and hired me because Marcia is not alone in her struggle for reimbursement. Being a patient today can be overwhelming, and sometimes it is more than the disease that destroys lives. Navigating an increasingly complex health care reimbursement system can take nearly as much energy and courage as confronting life-threatening and chronic illness. Even those who think they have prepared well for all possibilities are often caught without support when they need it the most. And this is true not only for the poor and unemployed, but for working people, families, and retirees as well.

CHO committed to this unique program because it no longer wanted to see its patients' diagnosis delayed because of the cost of tests; it didn't want to force patients to choose between lifesaving drugs and food, or to go into lifelong debt to pay for treatment.

While advocacy programs of this kind are typically only found in large hospital and academic medical centers, the fact is that most patients are now being treated close to home. And in our local communities, help must be available not only for patients' physical illness, but for their financial challenges as well.

The need for advocacy is increasing. Each day, I am in contact with 25 patients, all dealing with illness and how to pay for it. I have found that nearly everyone is underinsured and in need of advocacy services. I advocate to get patients reimbursed for their treatment through Public Health Programs and Patient Assistance Programs and with MassHealth system to obtain transportation to their doctor's offices. I am in constant communication with hospital billing offices and local elder affairs and other social agencies and insurance companies. And I have just begun a local access cable show in Braintree, Ma. to inform the public of important issues.

Recently, I have also been on a mission to get seniors throughout Massachusetts to sign up for Prescription Advantage, the state's drug insurance program. Prescription Advantage is an innovative program that covers the cost of drugs for poor, middle-income, and even wealthy patients. It is a model for other states, but many Massachusetts seniors do not yet know it exists.

New Medicare Law is Biggest Challenge

But the biggest challenge facing patients and those of us who advocate for them is just beginning to play out - the new Medicare law. This law, which is the largest overhaul of Medicare since its inception in the '60s, is extremely confusing, and I believe it will severely restrict patients' ability to pay for the drugs they desperately need.

One aspect of the law, with which seniors, are already dealing, is the new drug prescription benefit. Here are a few of the facts: The law will provide seniors with prescription drug cards from different pharmaceutical companies. The cards vary, because each pharmaceutical company offers different drugs and determines the level of discount for those drugs. Patient must figure out which drugs they need and what company makes and offers them, and then choose the card on their own. The patients are then locked into that card for one year. However, under the new law, the drug company can change the list of drugs and the level of discount they offer. The upshot is that patients lose control.

Other facts: The average cost of the card is \$35 a month, or \$420 a year. Medicare pays for 75% of medication costs while the individual pays 25% until costs reach \$2,050. At this point, coverage ends; and the individual must pay all further costs that year out-of-pocket. This is called the "doughnut hole," which those of us in the advocacy world believe will get larger and larger with time.

To make matters worse, the new law prohibits the government from negotiating for better prices with the drug companies, and it prevents patients from buying supplemental insurance to cover the doughnut hole in their benefits. Finally, it makes it illegal to purchase American-made drugs more cheaply from other countries such as Canada.

In an article in the February 21-22 weekend edition of the Patriot Ledger in Quincy, Ma.,- U.S. Rep. William Delahunt, D-Ma., said that "despite its meager benefits, the cost of the new law is truly spectacular,- projected by the nonpartisan Congressional Budget Office to exceed \$2 trillion over the next 10 years,"

As an advocate for my patients at CHO and patients in general, I believe this law will be devastating for our seniors whose numbers and needs are growing. They deserve better.

The prescription drug issue is just one of many flaws in the law. It will also be particularly detrimental to cancer patients. The new law is scheduled to cut payments to community cancer specialists for purchase and administration of chemotherapy in the community setting. This aspect of the legislation

will ultimately make it impossible for patients to receive cancer care close to home and force them to go to large, often urban-based hospitals.

You Can Be Your Own Advocate

No matter how old we are, the new Medicare law will have an impact on our parents and our children. I believe that the government, drug companies, and private citizens should come together to advocate for changes. Advocacy programs are a step in the right direction. Part of what I do is try to educate patients and empower them. In the long run, patients will be in a much stronger position if they have the information they need to advocate for themselves.

Those wishing to comment on the new Medicare bill can contact "The White House Opinion Line" at 202-456-1111 or fax a letter to 202-456-2461.

Ann Stewart heads the Patient Advocacy Program at Commonwealth Hematology Oncology. CHO, with offices and clinical sites throughout Massachusetts and southern New Hampshire, is the largest private practice cancer care network in New England. CHO is known for its leadership in community-based cancer care. It was the first group practice in the state to develop treatment guidelines for specific cancers and the first group practice in the area to develop a computerized software program for chemotherapy ordering. For more information, visit www.chomed.com.