

## **It Doesn't Have to Be This Hard**

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Caregiving is hard. How could it not be? The quality of life — and, in some cases, the life itself — of someone we care about is compromised, and we are playing the lead role in trying to hold things together. Caregiving will always be hard, but it doesn't have to be as hard as it is. Although it is difficult for many people to believe, what happens at the local, state, and federal level has a direct effect on many aspects of our caregiving — even what happens in our bedrooms and bathrooms.

Let's take a look at Medicare, for instance. Of course, not all caregiving families are dealing with Medicare, but private insurers often take their cue from what Medicare does. That's why its rules and regulations are important for all of us. Medicare, like all insurance, is designed to reduce the payer's risk, so it tightly regulates how its money can be spent. There are many products and services that Medicare doesn't cover. If it did, our lives would be easier, the care we give better, and our finances would be in better shape, too. There are regulations that say what a doctor can and cannot do and what can and cannot be billed, and there are even regulations that say if and when our loved ones can leave the house and still receive services.

### **Barriers to Supporting Caregiving Families**

#### Physician Time

Some of the rules and regulations that affect us the most have to do with the privacy rulings under the Health Insurance Portability and Accountability Act (HIPAA). These are not part of Medicare, but it is important to mention them here because some physicians are interpreting the privacy rules to mean they are not allowed to talk to family caregivers, and they are being very adamant about it. If a doctor won't even talk to you, you and your care recipient have a bigger problem than which services the doctor can bill for. Together you'll need to decide whether a doctor who doesn't recognize your role is really the best doctor for your loved one.

Assuming a doctor is open to talking with you, and even sees you as an ally in his patient's care, there are no CPT codes (the boxes they check on the payment form) that allow a physician to bill for time spent talking with/counseling family caregivers if the patient is not also present. When a doctor is not being paid, there really is only so much

time he/she can afford to spend with us. What this regulation is saying in no uncertain terms is that Medicare doesn't recognize the role of family caregivers. This is the crux of some other issues as well, as you will see below.

In addition to not paying for doctors to talk with us, Medicare also does not allow a physician to bill for time spent coordinating a patient's care with other doctors. Given that most care recipients are dealing with multiple physicians, this is a serious issue. Lack of care coordination is believed to lead to unnecessary hospitalizations, and to otherwise unnecessary nursing home stays. It is also thought to be one of the primary reasons for a patient to experience an adverse medication reaction. If your loved one's doctors aren't communicating with each other, how is each to know what the other is prescribing? The answer is that it becomes your job to tell them. By default, family caregivers are the health system's care coordinators.

Yet another problem related to the physician payment rules is that doctors are paid less for taking a patient's history and performing an examination than for performing a procedure, even if the former takes more time than the latter. Yet, time to describe problems adequately and be counseled about symptoms, and the pros and cons of potential treatment options, is what family caregivers and their loved ones need. Performing an endoscopy or interpreting an MRI might be more lucrative for a physician, but it is not the type of care people with chronic illnesses need day to day. It would seem that doctors should receive more money for dealing with complex cases. It would benefit family caregivers, and our loved ones, to have more time with them.

### Definition of Homebound and Related Issues

If you haven't come up against the homebound rule you'll think we are making this up; unfortunately, we aren't. Medicare says that unless someone literally can't leave the house without assistance, he/she is not eligible for home-care services. If that individual does leave the house for anything other than a medical reason and this is discovered, the services will be suspended. This was changed slightly a year or so ago to allow people to go to religious services a few times a month. The home-care services that Medicare will pay for must be considered "medically necessary" — to treat a pressure sore, for example — or be of therapeutic value, and Medicare will only pay for services for a short period of time, not over the long haul. Part of the reason for this is that Medicare was designed as an acute care system (performing heart surgery, saving the life of someone who has been in a car accident,

etc.) and has not adjusted to the changing demographics of our society, or the fact that people are now living many years with chronic conditions such as Alzheimer's, Parkinson's, and MS. Regardless of the reasons, it leaves caregiving families in the lurch, having to pay out-of-pocket for help with "activities of daily living" such as transfers and toileting.

CMS (the Centers for Medicare & Medicaid Services, the agency that oversees Medicare) is not willing to pay for a power wheelchair for someone to get around outdoors if that person doesn't need it inside the home. CMS doesn't seem to realize that in a house there are walls to hold on to, the distances are not very vast, and many homes don't have doorways wide enough to accommodate power chairs. It's as if they are saying, "We'd rather you vegetate than participate in life." Since Medicare provides services for people with disabilities as well as the elderly, this could mean the difference between someone going to work and having to be on welfare.

### Therapies

Medicare is starting to pay for a few preventive services, but it still does not cover physical therapy, OT, or other rehabilitation services if it cannot be shown that the patient is improving. Many ill and disabled individuals need these services over a long period of time so they don't lose more ground, to help maintain current functions, or to slow down the impact of a debilitating disease. If your loved one falls and breaks a hip, Medicare will pay for him to go to the hospital and have an operation, but not for therapies aimed at preventing the fall in the first place. Once again, this is an example of Medicare not being responsive to the needs of people with chronic conditions.

### Caregiving Goods and Services

Medicare does not cover basic supplies that are needed by many caregiving families — the most obvious being adult incontinence products. These can easily cost \$1,800 annually. Medicare *will* pay for supplies, however, if someone requires catheterization. It seems that releasing urine from the body with an implement is considered a medical procedure, whereas capturing urine if it just flows uncontrollably from the body is not. Isn't it all about the same thing: controlling urination?

Medicare does not cover any of the costs of home modification to make a house safe for a senior or person with disabilities, such as grab

bars in the bathroom or the building of a ramp at the front door. Yet research shows that everyone would much rather stay in their own home than go to an institution. The Supreme Court has even ruled that people should have the ability to stay at home if they wish. It would seem that being able to pay for the means to do so should be part of the bargain.

Here is a Medicare ruling that is particularly loathsome for family caregivers: Medicare will not pay for the cost of a fully electric bed, even if the caregiver's back has already been damaged by bending and lifting and her/his ongoing health is at risk. It is another example of how Medicare ignores family caregivers' well-being, our role in the health of our country's most vulnerable citizens, and even our very existence.

So if you thought that family caregiving and public policy don't go hand in hand, if you thought it was somehow wrong to think of family caregiving as anything other than a personal family issue, think again. Many public policies, Medicare being the prime example, have it in for you and your loved one, and the only way this will change is if family caregivers speak up and demand change.

A family caregiver who participated in an NFCA-sponsored focus group some years ago commented:

*I don't think being a caregiver is a political statement where I have rights ... It sounds like you're being an advocate for something. It just takes all the softness and the love out of it.*

She couldn't have been more wrong. You do have rights and by standing up for them you are expressing great love for your care recipient because your well-being and their well-being are intertwined. Caring is hard and always will be, but it doesn't have to be as hard as it is. You may not be able to cure your loved one's condition, but together we can cure the public policy ills that make living with it so much harder.

If this article has fired you up and you'd like to take action, send your senators and representative an e-mail or call their offices. (Go to [www.senate.gov](http://www.senate.gov) and [www.house.gov](http://www.house.gov) to get contact information for members of Congress.) When calling each legislator, ask to speak to the health legislative aide, if possible; if not, just leave a message with the person who answers the phone. Tell your legislators about your

situation and that Medicare is making things harder for you because it isn't designed to support people with chronic illness. Remind them that ours is an aging society and with aging eventually comes some type of chronic condition. They can't wait any longer. They must tackle the very difficult problem of healthcare reform in this country, they must make it family focused, and they must do it now.