

Testimony of Stephanie Dempsey
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Before the Senate Committee on Finance
Chronic Illness: Addressing Patients' Unmet Needs
Dirksen Senate Office Building, Room 215
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Chairman Wyden, Ranking Member Hatch, and Members of the Committee, thank you for allowing me the opportunity to testify today.

My name is Stephanie Dempsey. I am 44-years-old; I live in Blairsville, Georgia; and I have been battling multiple, chronic medical conditions for much of my life.

I have always considered myself a middle-class American. I had a well-paying job, I owned my own home and I was happily married. Unfortunately, this is not the case today. The very illnesses that I battle every day have taken that from me. I have lost my independence, my financial security and most importantly, my family.

I hope my story can help you and those listening today better understand what people with chronic medical conditions face day-in and day-out. And I hope my story gives you some sense of the challenges that I, and so many others, go through daily.

I would like to take a few minutes to share my story with you.

I was diagnosed with coronary artery disease at the age of 21. My heart disease is hereditary and has impacted all of the women in my family. My only sister died at the age of 28 from heart disease. My mother, who is 69, underwent quadruple bypass surgery at the age of 48 and my maternal grandmother died at the age of 72 from coronary artery disease.

At the age of 30, I underwent quadruple bypass surgery for severely blocked arteries caused by high cholesterol. Since then, I have had 27 stents, another bypass surgery, and countless other medical procedures. I take 15 different medications in the morning and an additional four in the evening plus multiple supplements recommended by my doctors. At times it can be difficult to keep track of all of my medications, so I use different baskets – labeled by condition –so that I can stay organized.

In addition to heart disease, I am fighting the effects of lupus, arthritis and a seizure disorder – all of which have become debilitating. I can no longer work – although I would desperately like to – and I depend on my parents to help care for me. I always believed, as I am sure some of you have, that I would be taking care of my parents as they grew older. Instead, they are taking care of me because I simply had no other choice. This has been difficult to accept, but this is my reality.

Battling a number of complex illnesses has not only taken a toll on me, it has taken a toll on my entire family. As you might imagine, my medical expenses are significant and are becoming more significant by the day. We fell behind on our mortgage and were forced to sell our home. It was difficult to make ends meet. At that time, my first priority was to buy medicine that my son – who is now 20 years-old – needed for his own health conditions. This required us to scrape money together to make sure that he had the necessary medications. Paying for my numerous

costly medications was out of the question and therefore I was unable to purchase them. As a result, I was hospitalized five times over the course of six months, which resulted in five additional stents. As it became more difficult for me to manage my illnesses, the growing burdens became overwhelming for my husband, and after 21 years of marriage, he decided to walk away.

I had no choice but to move from South Carolina to Georgia to live with my parents. I now live in the rural mountains of Georgia, and although my primary care physician is nearby, I have to travel over two hours to see my specialists. And because of my seizure disorder, I depend on my parents to take me to my appointments.

In addition to my primary care provider, I also must see multiple doctors. I have a cardiologist that helps me manage my heart disease, a neurologist and neurosurgeon who help me manage my seizure disorder, and I have a rheumatologist who helps me manage my lupus and arthritis. I interact with countless other health care professionals such as nurses, physician assistants, therapists, and others.

Although my doctors are all well-intentioned, they often don't talk with each other or share information about my care. This ultimately leaves me to be my own health care coordinator. To give you an example, my Lupus disorder keeps my body in a constant state of inflammation for which one of my specialists prescribed a medication to reduce that symptom. Unfortunately that medication can cause seizures. He did not remember my seizure disorder and the medicine caused me to have an increase of seizures. After a visit with my neurologist, he took me off the medication, knowing the seizure side effect. Getting this resolved took days, countless phone calls and much persistence on my part. Issues like this happen frequently and although I consider myself an educated person, navigating this maze is very difficult and exhausting. But it is my life at stake and I do not have a choice but to be engaged.

To give you another example, I recently had to change to a new primary care doctor, since my former doctor is only accepting private-pay patients. This has been a challenge as it will take some time for me to become familiar with my doctor and for her to become familiar with me and my medical history. In an ideal world, I would want my primary care doctor to manage all of my care, but I have come to realize that this is not realistic, because I require specialized physicians.

For a long time I was privately insured through my employer, and later through my husband's insurance policy. However, when my husband was laid off and his health benefits terminated, I was left without insurance. Fortunately, I was able to qualify for Medicare in 2004 because of the federal disability law. Although it took two years of "fighting" to qualify for Medicare, the program has been extremely helpful but it still leaves me constantly struggling to pay my portion of my medical bills. My last surgery in September 2012 cost \$51,000. Medicare covered all but \$1,138 of the fee.

I have encountered countless challenges along this journey and I'm extremely fortunate to be here today to share my story. I am confident that you will not forget me and countless other people who are dealing with chronic illnesses when you develop policies that will help all of us. Our goals are the same: to live long, healthy and productive lives.

I sincerely thank you for giving me this opportunity to share my story.