



In Their Own Words...

Real Stories from the Patients and Families Suffering from the Medicare Home Infusion Coverage Gap



Nancy E. Helms

Yorktown, Virginia

One Step at a Time

Each day, seventy-two year old Nancy Helms is getting one step closer to walking without the aid of her walker. She tires easily, but she is sure to do the exercises that will strengthen her legs and make her more mobile. Nancy is a native of North Carolina but she made Virginia her home when she married her husband Bill over 51 years ago. Sadly, Bill passed away this past June at the age of 74 following complications related to COPD or chronic obstructive pulmonary disease, a serious lung disease where the airways—tubes that carry air in and out of your lungs—are partly blocked, making it hard to get air in and out. COPD is also referred to as emphysema or chronic bronchitis.

Together, Nancy and Bill raised two boys—Hal and Craig, and have three grandchildren, four step-grandchildren and two great-granddaughters. Both educators, Bill was an elementary school principle and Nancy, who has a doctorate in education, was a teacher and guidance counselor. Nancy retired as the director of guidance and testing for the Hampton City Schools but later worked part-time as a professor at Old Dominion University in Norfolk and later as a professor at the College of William and Mary in Williamsburg.

Throughout her lifetime, Nancy's has had her share of health challenges but she has continued to persevere with steadfast determination. A number of years ago Nancy had three back surgeries to alleviate the intense pain she had been experiencing since she was young. The surgeries were not successful and as a result of the excruciating pain, Nancy was forced to leave her job at the College of William and Mary in 1997. She was also forced to end her volunteer work at a regional prison where she counseled inmates on their futures and how to lead a better life outside prison.

However, it was complications from diabetes that posed a number of health problems this past year. Nancy has been living with diabetes for 41 years. She is one of the estimated 23.6 million Americans living with this life-threatening chronic illness that affects the body's ability to use blood sugar for energy. One of the leading causes of disability in the country, the number of people diagnosed with diabetes in the United States continues to rise at an alarming rate, according to the Centers for Disease Control and Prevention (CDC). While Nancy successfully manages her illness, she does suffer from congestive heart failure and has experienced several complications throughout the years.

Toward the end of 2007, Nancy began having some foot ailments which were treated with oral antibiotics. Complications from a foot infection led to the amputation of Nancy's left big toe in January 2008. Following the surgery she was given oral antibiotics to fight infection, but shortly thereafter, she developed another infection where she was prescribed a course of intravenous antibiotics. Nancy was told that she would need to undergo her infusion treatments in the hospital as an outpatient because Medicare would not cover home infusion therapy. "I was stunned and angry to say the least," says Nancy. "I did not know how I was going to do it. Between my surgery, my back and my heart, I was barely mobile. I needed assistance getting in and out of a car. My only caregiver, my husband, was sick," she adds. "As retirees, we were on a fixed income. We could not afford home infusion, so I had no option but to go to the hospital each day."

In Their Own Words...

Despite the challenge, Nancy and Bill made the trip to and from the hospital each day. "It was very difficult for both of us. It took more than three hours of our day each day. We were exhausted. I felt so bad for my poor Bill who had to drive me to the hospital carrying his oxygen tank. I was in so much pain that at times I did not even remember going to the facility. I certainly would not want to experience that again," says Nancy. "Medicare should consider the needs of patients and fully cover home infusion therapy."

A few weeks later, the infection was not completely gone and she was prescribed another round of antibiotics. This time Nancy opted to self pay rather than go through the same experience. "It was expensive but well worth. I made the financial sacrifice because I felt my husband and I could not accept what Medicare was offering," says Nancy. "It just doesn't make sense. At a time when every penny counts, Medicare needs to cover home infusion therapy. Getting treated at home is significantly less expensive than a hospital stay and is certainly better for patients."



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Diciderio Molina

Lubbock, Texas

The Healing Power of Family

Diciderio Molina or “Desi” as he is lovingly referred to by his friends and family, has had his share of struggles and pain living with diabetes for close to 30 years. However, at 55, he considers himself blessed to be happily married to his wife Becky for 36 years and to have raised two wonderful daughters, Desiree who is married, works, and attends college in Irving, Texas and his youngest Destiny, a freshman in high school.

Desi is one of the estimated 23.6 million Americans living with diabetes, a chronic disease that affects the body's ability to use blood sugar for energy. Diabetes is a life-threatening illness and one of the leading causes of disability in the country. According to the Centers for Disease Control and Prevention (CDC), the number of people diagnosed with diabetes in the United States continues to rise at an alarming rate.

Following his diagnosis in 1979, Desi successfully managed his illness, kept his blood sugar under control and was able to lead an otherwise healthy normal life. That changed in 2001. “Complications from the diabetes resulted in having to leave my job as a car salesman to go on disability. Unfortunately, I was also forced to discontinue my service as an Army reservist,” says Desi. Other health problems emerged. In 2007, complications from a foot infection he had been fighting for three years finally led to doctors amputating Desi’s right leg. Despite the setback and his inability to work following the amputation, he remained optimistic about the future.

In early 2008, Desi was re-admitted to the hospital with a swelling in the knee of the leg that was amputated. Doctors immediately diagnosed it as a bad staph infection and prescribed a prolonged course of intravenous antibiotics. “I was devastated by the news that I had an infection, but I was glad that it was not serious enough to keep me in the hospital. I just wanted to go home, take my antibiotics and get rid of the infection,” says Desi.

Unfortunately, Desi was informed that he could not undergo his treatments at home. “Doctors told me that while Medicare covers infusion drugs, the related services, supplies and equipment are not covered. Home infusions are covered under my service-related benefits but they do not kick in for another few years,” says Desi. “My wife’s insurance was not an option as the home infusion would have cost us well over \$600 per week. With only one income, this was not affordable,” he adds. Desi’s only option was a prolonged and costly hospital stay where Medicare would cover the infusion treatments.

“I was in the hospital for almost two months; too long for anyone to be away from their home and their loved ones,” Desi says. Throughout Desi’s hospitalization, Becky continued to work full-time, maintain the home and care for their 15-year old without the support of her husband. “The hospital stay put a tremendous amount of unnecessary stress on my wife and personally, the experience was demeaning and disheartening. My family is my pillar of strength. I needed to be with them,” says Desi. “Being in the hospital was a waste of time and money. Not only did it put me at risk of acquiring other hospital-related infections, but it cost Medicare \$2000 a day for me to be in the hospital. It does not make sense to me that our healthcare system will incur the high cost of hospitalization, but will not cover the cost of home infusion at a fraction of the cost. I firmly believe that full Medicare coverage of home infusion therapy is less costly, safer for the patient and keeps families together.”



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Robert F. O'Keefe

Pittsburgh, Pennsylvania

Living Life to its Fullest

Robert O'Keefe, 58, married Mary Ellen his college sweetheart in 1973. Throughout the past 36 years, Bob and Mary Ellen have formed a true partnership founded on love and friendship. Together, they were blessed with four children and a four-year old grandson named Bobby. Following a long career in academia, Bob elected to retire from his position as school principle in June 2006. Mary Ellen, on the other hand, decided to continue her work as a teacher. Bob's retirement did not last long as he was asked to step in for a principle at another school who had fallen ill. By August of 2006, Bob was back to work. However, life as he knew it, was about to change.

In October 2006 Bob recalls feeling extremely weak and tired all the time. He felt significant pain in his left hip and leg. Bob's doctor attributed the pain to sciatica or to a heart related matter. "A day or so later the pain was intolerable to the point that my wife and I went to the emergency room," says Bob. Following a series of tests, Bob was diagnosed with Stage III multiple myeloma, a cancer in which abnormal cells collect in the bone marrow and form tumors. Bob was treated with the standard treatment of care for this disease: chemotherapy in combination with radiation. "I was in the hospital for a month following my diagnosis. After that, I spent another 100 days in the hospital fighting complications that ranged from infections, to liver problems, to issues with my kidney which eventually led to the need for hydration infusion. It was a very difficult and stressful time for my family."

Today, Bob is on oral and intravenous chemotherapy. Treatment also includes intravenous hydration which helps to flush out toxins that can damage his kidneys and that helps to create chemical balances to maintain a healthy heart. The hydration infusion process lasts 10 hours. Thanks to home infusion, Bob is able to undergo his treatments overnight while he sleeps. "The infusion process is simple and painless. My wife and I were taught how to administer the infusions by a home health aide. Now we are pros," says Bob.

"I can't begin to describe the convenience of home infusion and the quality of life I am able to maintain by undergoing my treatments in the comfort and safety of my own home," says Bob. "Through home infusion I am able to enjoy going out to dinner with friends, listen to my favorite tunes, and work around the house. I consider myself very fortunate to have the ability to afford this benefit through my private insurance. My heart goes out to all those who rely on Medicare and are forced to turn their lives upside down to receive needed intravenous treatments at a hospital or nursing home because Medicare will not cover home infusion therapy."

"People with compromised immune systems should not spend any more time in a hospital than absolutely necessary," says Bob. "Home infusion therapy represents a win-win for patients and Medicare alike. Not only are infusion treatments at home less costly than treatments at the hospital, but it is preferred by both patients and their physicians. Patients want to be able to heal at home, where they are most comfortable, surrounded by their family and less likely to acquire serious infections that run rampant at hospitals and that can put their lives in danger. After all, at the end of the day, it is all about living the best life we can. Medicare should understand this."



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Susan R. Warshaw

Salt Lake City, Utah

The Love of her Life: A story of perseverance

Susan Warshaw's love and admiration for her husband Keith is unmistakably clear in her voice and in every word she speaks. At 64, Susan sadly lost her husband of 25 years the day after Christmas this past year. He was 84. Keith and Susan's marriage was a true partnership. Their love, respect and friendship endured the test of time and gave them the inner strength they needed to face many challenges throughout their lives together.

A football injury his senior year of high school left Keith paralyzed from the waist down for the remainder of his life. However, Keith refused to let this life-altering injury stop him from living life to its fullest. In many ways he was able to accomplish much more than any able-bodied person. "Keith was an amazing, strong spirited man who achieved all that he set out to do," says Susan. "He was both a savvy businessman and the humblest of humanitarians. He successfully ran a merchandise business founded by his father and later created and operated one of Utah's most unique and memorable retail emporiums. His deep understanding and concern for people with special challenges led him to assist disabled veterans of World War II in recovering from the physical and emotional scars of war, enabling them to live a full and rich life. To say he was a "miracle man" is an understatement," says Susan.

Keith approached his health and quality of life in the same manner--with resolve and steadfast perseverance. Susan was intimately involved in the physical care of her husband and is herself a shining example of overcoming adversity through determination and hope. As a result of his paraplegia, his continuous medical problems caused him to require the need for antibiotics throughout his entire life. He became more and more resistant to most oral antibiotics as the years went by, and in the last several years, intravenous antibiotics were the only effective means of combating infections. "Unlike most patients, my husband was able to pay for home infusions even though it seemed so punitive and discriminatory," says Susan.

"If my husband couldn't have afforded home infusions, he wouldn't have physically been able to go to an infusion facility two or three times a day. His only option would have been to undergo treatments as an inpatient in a hospital," says Susan. "Something, I do not think anyone would want to do if they had the option of home care," she adds. "Hospitals are very dangerous, particularly for someone with a compromised immune system," says Susan. "In the last few years alone, my husband contracted life-threatening infections in the hospital including pneumonia, MRSA, and a full-blown staff infection," "Hospitals are also depressing places that whittle away at your spirit," she says.

"I do not understand why the 'powers that be' at Medicare are not willing to pay for home infusion when it represents a fraction of the cost of what they currently pay to infuse patients in a hospital or nursing care facility," says Susan. Home infusions are safe and simple to administer. There are no needles and the amounts are all measured in advance. "I never required home health care professionals to help with any of my husband's infusions because it was so simple and I couldn't ask anyone to be available at all hours of the day," she adds.

"Seven years ago, I was told by some of the most prominent physicians in the state of Utah that my husband had two weeks to live and suggested that I take him home to let him die. I refused to listen," Susan said. "While there were challenges, I am convinced that my husband's longevity and certainly his quality of life was due to his being able to spend most of his last several years in our home. Everyone should have that choice. Medicare can contribute to healthcare reform by agreeing to cover home infusion therapy; treatment that represents high-quality care at lower costs.



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Judy K. Colburn

Glenvil, Nebraska

A Mother's Gratitude for her Daughter

Sixty-seven year-old Judy Colburn remembers looking at her swollen finger one morning and thinking that what she thought looked like a spider bite was definitely now infected. Not wanting to take any chances, she went to her doctor who gave her antibiotics via injection. A follow-up visit the next day resulted in her doctor recommending that she see an infectious disease specialist. While the specialist suspected Methicillin Resistant Staphylococcus Aureus (MRSA), he preferred to have Judy tested at the hospital to confirm his diagnosis. As it turned out, Judy's skin infection was indeed caused by MRSA. The infected area usually starts out as a small bump resembling a pimple or spider bite, and increasingly worsens.

Judy was prescribed a course of Vancomycin, a strong antibiotic administered intravenously, twice a day for two weeks. Upon hearing the news, she automatically assumed that she would receive her treatments at home since she wasn't sick. However, the very next minute the doctor explained to her that she would need to receive her treatments at the hospital on an outpatient basis as Medicare would not cover the cost of home infusion. "At first I did not understand why I had to go through the expense and inconvenience of going to the hospital twice a day. I was very upset. I do not drive and the cost of a cab to take me back and forth to a hospital that is 15 miles away was not an option I could afford," says Judy. "I knew that the treatments at home would be less expensive than receiving them at the hospital, but as a retiree on a limited income, I could not pay for home infusion therapy out of pocket.

As with other Medicare patients, the cost of Judy's antibiotics would be covered, but the supplies and equipment needed to receive infusion treatments at home would not. "My daughter Patty and I spoke exhaustively about the situation and decided that she would drive me to and from the treatments. I felt terrible, but there was nothing I could do."

While difficult, Judy's daughter took time off from work at no pay to take her mother to the hospital twice a day. Traveling 60 miles a day presented an additional financial burden. "Patty would take me once at 7:45 in the morning and a second time at 9:00 at night. Each time, she waited the hour and a half the infusion lasted," says Judy. "In between that, she drove her son to work. She was exhausted. The sacrifice my daughter has had to make is more than I could expect of anyone. She has given so much of herself".

"I cannot understand how Medicare is willing to cover the cost of a more expensive course of treatment at the hospital, but is unwilling to pay the cost of infusion at home which is less costly and safer for someone like me battling infection. It just doesn't make sense," Judy states. "My daughter means the world to me. I am so grateful for all she has done for me, but putting such unnecessary burden on your loved ones, is one reason legislation to modify the current Medicare laws is needed.



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Alaina M. Evans

Bluffton, South Carolina

Wife, Mother, Daughter, Sister, Teacher

On any given day, 30 year-old Alaina Evans appears to be a typical young mother caring for an active 4-year old. Yet, Alaina is among the 30,000 children and adults living in the U.S. with cystic fibrosis, a chronic disease that produces unusually thick, sticky mucus that clogs the lungs, obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food.

Alaina was diagnosed with cystic fibrosis as an 18-year old attending her first year of college. While this was a major shock and life altering diagnosis, she continued to pursue her education, graduating with a Masters degree in Education in 2001. During the next few years, Alaina continued to lead a normal life. She taught Kindergarten and first grade, married, and in 2005 she and her husband Jeff welcomed their daughter Reagan. However, for Alaina and others living with cystic fibrosis, normal includes taking one or more antibiotics at all times to suppress infections as much as possible, even when they are considered healthy. Alaina was on a course of intravenous antibiotics every 6-8 months. "I normally would go into the hospital for 2-3 days to get the medicine levels adjusted, and then continue the infusion treatments at home for two weeks", says Alaina. All medical expenses, including home infusion therapy, were covered through a private insurer provided by her employer.

Alaina had been teaching for close to five years when she was first diagnosed with Mycobacterium Abscessus and had major hemoptysis. As a result, she had no recourse but to go on disability. She was on Cobra for 24 months and afterwards held private insurance until she became eligible for Medicare. It was not until December 2008 when Alaina was admitted to the hospital for hemoptysis and an infection, that she first learned of the limitations that existed under Medicare for someone needing infusion therapy. "My doctor told me I needed a round of intravenous antibiotics but while Medicare would cover the antibiotics I was to receive, they would not cover the supplies and equipment needed to receive my infusion treatments at home. Medicare would only cover my infusion therapy if I stayed at the hospital. I was absolutely crushed. How was I going to explain to my four-year old that mommy would be away for two weeks?"

At an average daily cost of \$100 for the supplies and equipment needed for daily treatments at home, Alaina had no recourse but to admit herself to the hospital for two weeks. "It broke my heart knowing that I was going to be away from my daughter for two weeks. We had never been apart that long. My being in the hospital for two weeks was devastating to my whole family. Finally, my husband and I agreed to pay \$411.00 to go home and complete my last four days of infusion because my daughter was having anxiety issues." With over \$16,000 in self-paid medical bills, this additional expense placed an unnecessary burden on their finances.

"I know that there will be times when I will be too sick and will need to stay in the hospital," says Alaina. "However, other times when it is simply a matter of getting a normal course of antibiotics, it does not make sense for me to stay in the hospital for two weeks when I can easily receive my infusion treatments at home. I am very competent and comfortable doing my medications at home and it works out better for my family. I don't see how Medicare is willing to pay for a more expensive hospital stay than cover the costs of home infusion which is less costly, safer, and better for the patient.



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Doug Kerkoch

Bend, Oregon

Home is Where the Heart is

Watching ones parents get older is difficult and painful to say the least, but having both parents diagnosed with dementia, is heartbreaking. Doug Kerkoch knows firsthand the difficulty in witnessing the lives of his once vital and very active parents be whittled away by this hideous disease, a tiny bit at a time. Today, as many as 5.2 million people, including 200,000 individuals under the age of 65, are living with the disease. And, as the baby boomer generation ages, it is expected that 10 million will develop Alzheimer's in their lifetime.

Doug is a successful CPA with a wife and grown daughter. He is also executor and guardian of his parents, Frank, 82 and Jean, 81, who both suffer from early-stage dementia. While Doug's parents are marginally capable of self-care with each relying on the other for support, they moved to an assisted living facility during the summer of 2008. "Following their diagnosis, my parents continued to live at their home and were able to care for one another with assistance from my sister and I. However, I began noticing that they were growing increasingly forgetful and confused. They were not taking their medicines correctly nor eating right. Eventually, it became clear to me that my parents needed more care than my sister or I could provide. It was not an easy decision. However, we all agreed that assisted living would extend my parent's independence but in a safe, supportive, supervised setting," Doug says.

Frank and Jean were doing well in their new home. But, in the fall of 2008, Jean began to limp and her shin appeared red and swollen. Following a visit to her physician, Jean was diagnosed with an infection and was prescribed oral antibiotics. However, the infection grew worse and an MRI determined that the infection was on the bone. She was prescribed an eight week course of intravenous antibiotics. Doug's parents have Medicare coverage but while Medicare covers the infusion drugs, the related services, supplies and equipment are not covered. "We were told that Medicare would only cover the infusion treatment for my mother if done at the hospital, a nursing home facility or a health clinic," Doug says. "For my family, none of those options were acceptable," he adds.

"Taking my mother away from her home and her husband to a hospital or nursing home for eight weeks would have had a negative emotional and physical impact on both my parents," Doug says. "They have been married for 60 years and have rarely been apart. They are best friends and have a tremendous love for one another. Despite dementia, their bond is stronger than ever and they continue to support one another as they navigate through their disease. I could not separate them," he adds.

Doug did not want to put his parents through such a painful ordeal. As legal guardian, he made the decision to pay for his mom's home infusion therapy using their savings so his parents could remain together within the safety and comfort of their home in the assisted living facility. "The doctor prescribed daily infusions of one hour. It seemed crazy to transfer my mom, and possibly my dad, from their home to a hospital or nursing home for treatments that only lasted one hour of the day."

In Their Own Words...

Studies have shown that regular well-established routines and stable familiar surroundings can help to keep the symptoms of disorientation to a minimum for someone suffering from dementia. "I have no doubt that admitting my mom to the busy bustling environment of a hospital would have been frightening and confusing for her to the point that I think it would have been life-threatening," Doug says.

"The 8-week home infusion treatment cost about \$7000, but it was well worth it. A home care specialist visited my mom daily to administer her medication," Doug says. "Nothing was more important to me than safeguarding my mother's safety and well-being and maintaining her humanity and integrity," he adds. "My mother was fortunate that we were able to pay for the treatments. Countless others do not have the ability to do so. I cannot imagine how difficult it must be for patients and for caregivers who must see their loved ones distressed. The cost of home infusion compared to a hospital stay is significantly less and is better for the patient. As a CPA, Medicare's unwillingness to cover home infusion therapy makes no financial sense."



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Stephen E. Reynolds

Butler, Pennsylvania

Bouncing back despite setbacks

Steve Reynolds has had his share of medical challenges, mostly as a result of being diagnosed with lung cancer in 2003. At 53, Steve has a grown daughter and considers himself a proud grandfather to her young son. Looking back at the chain of events that led to his diagnosis, he recalls how he inadvertently learned of his condition. "In 1985, I was diagnosed with a brain aneurysm. It was treated with a surgical procedure where the blood vessel that feeds the aneurysm is cut off with a small, metal clip that halts the blood supply and prevents the risk of future bleeding," says Steve. "In December of 2003, I kept hearing a buzz in my head and went immediately to the emergency room to have it checked. I didn't want to take any chances. It turned out to be a false alarm, but the emergency room doctor noticed I was wheezing and decided to do a quick x-ray. There are no words to convey the shock and despair one feels upon hearing life-altering news. I learn that I had a baseball size tumor in my right lung," Steve recalls. "If it were not for my visit to the emergency ward that day, I would never have known I had this growth until it was too late," he adds.

In 2004, Steve had surgery to remove part of his right lung, and in 2006, a second surgery removed part of his left lung. "Following the surgeries, I was on chemotherapy which was administered intravenously at the hospital. During the past few years, complications have developed including blood clots, sinus infections, and pneumonia that have required extended hospital stays. Each time, I remained in the hospital or was placed in a nursing home for an extended period of time to receive my treatments, even though I had no other medical needs that would require a stay in a nursing facility," he says.

"I have been covered under Medicare since I became disabled six years ago. Medicare covers the infusion drugs, but not the related services, supplies and equipment needed to administer the treatments at home. I am extremely frustrated by the fact that Medicare will not cover home infusion therapy when it makes so much sense to do so. By not covering the administration of intravenous medicines at home, Medicare is placing an unnecessary burden on patients, forcing us to stay in hospitals or nursing homes when it is safer for us to be at home," Steve says. "Unfortunately, I cannot afford the cost of home infusion and therefore have no options. The irony is that home infusion would cost Medicare significantly less than it currently pays to treat patients in hospitals,"

"I have spent countless days away from my home; the longest hospital/nursing home stay was about thirty days--too long to be away from the comfort of one's home. Anyone who has stayed in a hospital or nursing home for an extended period of time understands the depression and loneliness that sets in," Steve says. "The medicines you take may treat your physical self, but your emotional well-being does suffer. Medicare needs to consider the quality of patient care if it is ever going to be a valuable contributor to our healthcare system," Steve comments.



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Jerrel M. Sansbury

Florence, South Carolina

Getting the Most out of Life

Jerrel Sansbury is better known by his family and friends as Mitchell. Mitchell has lived in South Carolina all his life. It was here that he married his best friend's sister, Susan, thirty-six years ago. Now at 56, Mitchell is retired and takes pleasure in spending time with his family and friends, tending to his yard, and playing lots of golf in the plentiful courses that make South Carolina synonymous with golf. Yet, Mitchell is quite different from your ordinary retiree. Mitchell is among the 30,000 adults and children living in the U.S. with cystic fibrosis, a chronic genetic disease, where sufferers have thick mucus clogging their lungs.

Mitchell was diagnosed with cystic fibrosis when he was in his thirties. While this was a major shock and life-changing diagnosis, he has not allowed the disease to take control of him. He effectively manages his disease and is living his life to the fullest. Like others living with cystic fibrosis, Mitchell follows a regular treatment routine to stay healthy and maintain optimal lung function. Medications - inhaled and intravenous drugs - help clear mucus and fight infection. Regular pulmonary tests help to keep his health in check. In 2006, he had a bout with pneumonia that led to a hospital stay. He was prescribed a 14 day course of intravenous antibiotics which he started at the hospital and was able to continue at home. At the time, all medical expenses, including home infusion therapy, were covered through a private insurer. "Home infusion worked out great. It allowed me to be treated in the comfort of my own home and to continue in my day-to-day activities," says Mitchell. "This is certainly the best method of treatment," he adds.

In January of 2009, Mitchell was admitted to the hospital for a course of intravenous antibiotics when a routine check-up determined that his lungs were functioning below 50%. "As in the past, I started the treatments in the hospital with the intent that I would be discharged after 2-3 days and would continue the treatments at home. However, now that I was retired and on Medicare, my situation changed completely," says Mitchell. It was then that Mitchell learned that Medicare covers the infusion drugs but does not cover the supplies, equipment and service needed to administer treatment at home. "My choices were to pay for the home infusion myself or stay in the hospital the full ten days to complete my treatments," says Mitchell.

As he could not afford to pay for the administration of the treatments at home, Mitchell decided to stay in the hospital to complete the antibiotic infusion therapy. "I was very upset. The ten days I remained in the hospital were very difficult. I was depressed, and frankly, I was concerned that I would catch some illness that was floating around in the hospital. Someone with my condition should avoid hospitalization at all costs," says Mitchell. "As it turned out, I did pick up a terrible head cold while at the hospital that I am still fighting a month later. This could have been avoided if Medicare covered home infusion therapy," he says. "It does not make sense for me to undergo treatments in the hospital when I can easily receive my infusion treatments at home. Not only is it better for me, the patient, but it is less expensive for Medicare. With a hospital bill of \$52,000, I don't see how Medicare can continue to misspend dollars that can be better used elsewhere."



In Their Own Words...

Real Stories from the Patients and Families Suffering from the Medicare Home Infusion Coverage Gap



Barbara L. Tripp

Bailey, Colorado

Making Smart Choices

Whether it is Colorado's legendary snows or its mild summers, Barbara Tripp takes pleasure in the four distinct seasons that make Bailey, Colorado her ideal place to live. It is here that she has lived for the past 61 of her 86 years and where she has raised five children who have blessed her with eleven grandchildren.

After years of living with joint pain and the associated loss of function that accompanies arthritis, Barbara had hip replacement surgery in 2002. In 2006, she had her right knee replaced and in 2008, a day after her 85th birthday, she went ahead and had her left knee replaced. Until now, each of her surgeries had been successful with no complications.

"On its own, the second knee replacement surgery went smoothly," says Barbara. "It wasn't until the morning after surgery that my troubles began during physical therapy. My stitches broke open, leaving a gaping wound on the knee. The remaining stitches were later taken out, but I was in considerable pain," she says. Barbara was allowed to go home under the condition that she would return for a follow-up visit the subsequent week. Seven days later, Barbara was admitted to the hospital to undergo surgery that would remove a bad infection she had acquired. Barbara remained hospitalized for eight days while she received massive doses of intravenous antibiotics to fight the infection in her knee and save the prosthesis. "When I was discharged, I was told that I would need to continue receiving intravenous antibiotics twice daily for 30 days," Barbara recalls.

She was informed that according to Medicare, she had two choices: she could stay at a nursing home for 30 days while she received her daily infusion treatments, or she could undergo her infusion therapy at the hospital as an outpatient. "Needless to say, neither was an ideal solution," says Barbara. "Someone in my condition is vulnerable to the risk of infection and should not be institutionalized, so staying at the hospital or nursing home were not options I was about to consider. I don't drive and in this small community, transportation is not easily available. Even if someone could take me, going 70 miles each way would be tiring.

Barbara opted to go with home infusion therapy. "As you might imagine, the \$3900 home infusion bill was quite steep, especially since I am retired," says Barbara. "However, despite the financial burden, I felt this was the only way to get the treatment I needed in an environment that was safe and comfortable." Being at home allowed her to garden, care for her cats and dogs, and enjoy the unparalleled beauty of the mountains that surround her home. "All in all, I have no regrets, except one," she says. Through Medicare, people like me do not have the same options as those who can afford private insurance. By not covering home infusion therapy, Medicare is placing an unnecessary burden on patients, forcing us to stay in hospitals or nursing homes when it is safer for us to be at home. It is also unfortunate that precious dollars are being spent in ways that are more costly and that go against our wishes and that of our doctors. There has to be a better way."



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James E. Whitehead

Philadelphia, Mississippi

Living with Courage

At 72, Jim Whitehead, owns and operates an insurance agency out of his home. When he is not working, he enjoys spending time outdoors doing yard work. However, in the past few years he has found it increasingly difficult to do many of the things he took for granted such as walking and climbing stairs. Arthritis pain in his shoulders and knees left him feeling physically and emotionally helpless. Living with arthritis takes courage. As the disease progresses, it wears down cartilage that acts like a cushion, resulting in the bones rubbing against each other. "Simple things that most of us take for granted such as walking, bending, and even sleeping comfortably becomes a daily struggle," says Jim. By 2006, damage to both shoulder joints was so extensive that he elected to have surgeries to replace both shoulders. The surgeries went well, so when it came time to consider knee replacements, he did not think twice. In 2007, Jim had total replacement surgery on his left knee. The surgery went smoothly; alleviating the constant pain he had been living with and regaining the mobility he had lost.

A surgery to replace his right knee took place in July of 2008. Once again, there were no complications. However, three months later, Jim started having severe pain in his right knee. "My leg was red and inflamed. I could not move it and the pain was excruciating," he says. Jim was admitted to the hospital and his knee replacement was "flushed out" to clear up the inflammation and possible infection. He was released from the hospital. However, the aspiration procedure did not alleviate the pain nor remove the infection from the joint. One month later, Jim was back in the hospital and this time the diagnosis was Staphylococcus or "staph". Implanted materials, like those found in a joint replacement, can allow infections to persist. As a result of the infection, doctors performed surgery to remove Jim's prosthetic joint to replace it with another. While at the hospital, he was prescribed a course of cefazolin once every eight hours for six weeks.

By this point, Jim's difficulty with his right knee had been overwhelming and had taken its toll. He wanted the ordeal to be over. He wanted to go home. "The holidays were coming and the last place I wanted to be was lying in a hospital bed," says Jim. Jim had hoped he would be able to undergo his treatments at home. "Unfortunately, I was told that Medicare would not cover infusion treatments at home. They would only cover treatments done at the hospital. Receiving my treatments at home would demand me paying out of pocket. I was devastated. After all the time I have spent in hospitals with each of my surgeries, I knew the expense of undergoing treatments at the hospital. It was clear that Medicare was spending more money to treat me in the hospital than at home." Jim elected to stay in the hospital because he did not have the ability to pay for home infusion therapy. "By having to stay in the hospital, I was at risk of getting other hospital acquired infections, he says. "The hospital stay was also having a negative financial impact on my business as I was unable to work."

The day after Christmas Jim went home. However, during a follow-up visit in mid-January 2009, his doctor told Jim that the infection remained. He was admitted back in the hospital for surgery to remove the infected prosthetic joint for a second time. Once again, Jim was being forced to undergo another six week round of antibiotic infusion treatments at the hospital, which is still underway. If the antibiotics do their job, Jim will have a new knee replacement in about six weeks. Each day Jim is in the hospital, he faces the challenges of maintaining a positive attitude without surrendering to the disease. "The proposed legislation to fix Medicare's coverage of home infusion offers some measure of hope for people in need of home

In Their Own Words...

infusion therapy,” Jim says. “It makes no sense to me that Medicare is willing to pay for a more expensive hospital stay, but is unwilling to cover the costs of infusion at home, which represents a fraction of the hospital costs and is safer and healthier for patients,” adds Jim. “As someone who is experiencing firsthand the negative impact of institutional care, I cling to the hope that should I ever need infusion therapy again, I will have the opportunity to undergo treatment in the safety and comfort of my home.”