

United Ostomy Associations of America (UOAA) Support of Medicare/Medicaid Supply Coverage for Fistulas

Background

UOAA is a 501c(3) non-profit organization advocating for the 725,000 to 1,000,000 people living with an ostomy or continent diversion in the United States as well as the approximate 100,000 new patients facing ostomy surgery annually¹. UOAA is contacted frequently by many medical professionals and patients regarding the lack of access to supplies for managing fistulas. A fistula is an abnormal connection between two body parts, such as an organ or blood vessel and another structure². Fistulas may occur in many parts of the body such as:

- the colon and the external surface of the body, causing feces to exit through an opening other than the anus
- the bladder and the external surface of the body, causing urine leakage from the bladder onto the skin

People living with ostomies and continent diversions understand what it is like to live with the loss of normal function of the gastrointestinal system or urinary system. They are able to live life fully, to work, to play and to contribute to their communities because they have access to prosthetic devices; i.e. ostomy pouching systems, which replace the function of the body organs and systems they have lost. This is not the case for people who must live with fistulas which have formed because of infection or inflammation, cancer, trauma, radiation injury or any other non-surgical means.

Issue

Fistulas are a relatively rare but devastating complication of many disease processes, trauma, treatment side effects, or surgical complication. Fistulas affect less than 10% of the Medicare ostomy population. (Source: Medicare hospital data pulled from Definitive Healthcare - www.definitivehc.com) The majority of fistulas either resolve spontaneously or are corrected surgically. However, people may have to live for months managing a fistula, waiting for spontaneous closure or surgical repair. A very unfortunate group of patients whose fistulas do not resolve spontaneously and are not candidates for surgical repair must live the rest of their lives with the fistula.

Although medical products such as fistula containment pouches are available on the market to manage and contain fistula output, Medicare/Medicaid coverage is limited to only fistulas that are caused or treated by a surgical procedure. This does not address the population of people who have fistulas which have occurred because of non-surgical reasons such as inflammatory bowel diseases (e.g., Crohn's disease or ulcerative colitis). These patients must pay out-of-pocket for their medical products.

Impact on Patients

The care of a fistula, whether short term or long term, requires a multidisciplinary approach to care. For the affected patient, difficulties often include complex wound management depending on the location within the gastrointestinal/urinary system and location on the body. Other factors are severe malnutrition, infectious complications, pain (acute and chronic), and emotional aspects including anxiety and depression³. Some fistulas may result in death. Of great significance are the increased healthcare costs and financial burden for both facilities and patients when patients are unable to afford the out-of-pocket

costs for treatment and supplies. This often results in months of care at a facility until either spontaneous closure or surgical closure of the fistula can be performed.

“Until my fistulas were able to be surgically closed, I did not receive any insurance coverage for medical supplies for managing my fistulas. Everything was out-of-pocket and it was all very expensive. As if having a fistula isn't dehumanizing enough, not receiving appropriate coverage makes us patients feel unheard and unrecognized for the trauma we are suffering. It doesn't matter what kind of fistula one has (obstetric, Crohn's or otherwise). The reality is that fistulas ruin lives and they wreak havoc on our physical and mental health. Even though fistulas sometimes close with medication or can be surgically repaired, oftentimes, they reopen and remain a chronic source of infection. And in their wake, they leave behind a trauma so real and so deep that it feels impossible to heal ourselves and move forward.”

- Patient Advocate Tina Aswani Omprakash

“As a wound/ostomy care RN, the most difficult patients I faced were those who had developed fistula due to complications from surgery or disease. These patients were not only difficult for me, but also for the surgical team and ancillary services including nutrition, PT/OT and chaplain services. Ultimately, fistulas were the most difficult for my patients. I watched many face the physical and emotional burdens for six months or longer. One such patient stands out in my mind - A young woman in her early forties who developed several abdominal enterocutaneous fistulas after surgery. She was in and out of the hospital for approximately 9 months with hospital admissions lasting as long as two months. She would cry with each dressing change due to pain, which would result in severe anxiety. She would beg to eat and drink, which was not allowed for the hope was spontaneous closure using total parenteral nutrition (TPN) as the alternative choice for nutrition. She lost her home and pets due to the financial burden of care and she had few support systems. She was finally able to live with her son and receive home health services who were willing to learn the complicated wound care and pouching system. Eventually, she received surgical repair of the fistulas. However, one week later they recurred in different locations and we were all back to square one. It was a nightmare.”

- Joanna Burgess-Stocks, BSN, RN, CWOCN

CALL TO ACTION

United Ostomy Associations of America, Inc. (UOAA) recommends that the Centers for Medicare and Medicaid Services (CMS) revise the existing Ostomy Supplies Local Coverage Determination Policy (L33828) and Ostomy Supplies Policy Article (A52487) to allow for coverage of fistulas using ostomy appliances. This could be accomplished with revision of ICD-10 codes to the policy and adjusting the policy language to include the classification of fistula care products as prosthetic devices under Durable Medical Equipment Prosthetics Orthotics Supplies. Although the financial impact on total Medicare/Medicaid costs from this coverage change would be nominal, the impact on the people living with fistulas would be substantial. This change would increase access to care for this population as well as decrease the burden of this medically complex care for healthcare facilities and homecare agencies.

¹Ostomy 101 - Provided by United Ostomy Associations of America. (2017). Retrieved August 17, 2020, from https://www.ostomy.org/wp-content/uploads/2019/03/ostomy_infographic_20170812.pdf

²Fistula: MedlinePlus Medical Encyclopedia. (n.d.). Retrieved August 25, 2020, from <https://medlineplus.gov/ency/article/002365.htm>

³Rachel M. Owen, M. (2013, February 01). Definitive Surgical Treatment of Enterocutaneous Fistula: Outcomes of a 23-Year Experience. Retrieved August 17, 2020, from <https://jamanetwork.com/journals/jamasurgery/fullarticle/1379762>