# How to Leverage Relationships

# with Advocacy Groups

May 2025

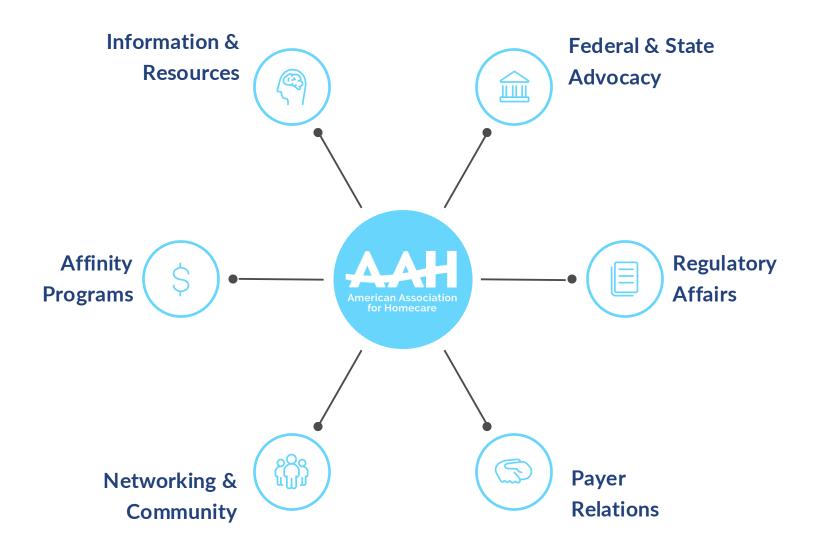




# PRESENTED BY



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# CONNECT. ADVOCATE. EMPOWER.

AAHomecare is the national advocacy voice for the HME community, working to strengthen the HME benefit at the state and federal level, protecting end users and the companies who care for them in partnership with allied organizations.



# BY THE NUMBERS

AAHomecare is hard at work bringing wins that impact your bottom line, helping ensure access to patient care.

**\$ ROI for the Industry Since 2022** 

\$4.5 BILLION

**Member Locations** 

3,000

**Patients Served by Members** 

16,000,000

- Over 200 meetings/year with state and federal legislators, governmental agencies, and payers on HME priorities
- 10 member-driven councils, providing networking opportunities and strategic collaboration to address key issues impacting your business.
- **35+ advocacy and operational resources** created in last 3 years by AAHomecare's product-focused councils





#### **Advocacy Groups Defined...**

- Advocacy "the act or process of supporting a cause or proposal", per Merriam-Webster
- An advocacy group is an organization that works to influence public opinion, policy decisions, or laws on behalf of a particular cause, issue, or group of people. These groups typically aim to raise awareness, promote certain values, or push for changes that align with their goals. They might engage in activities like lobbying government officials, organizing campaigns, conducting research, providing education, and mobilizing community support.





#### **HME Industry Advocacy Groups**



# AAHOMECARE American Association for Homecare

#### STATE ASSOCIATION PARTNERS

Our state association partners play a critical role driving grassroots advocacy at the state and federal level while working with AAHomecare's payer relations team to engage Medicaid programs and elected state officials.















































#### ALLIED INDUSTRY PARTNERS

We are grateful for the collaboration with allied Industry partners as we work to advance shared HME priorities.









### Other Stakeholder Advocacy Groups...















### AAHomecare is proud to work alongside allied stakeholder groups in advocating for HME access:

















### 3 Strategies To Engage With Patient Advocacy Organizations

By Paul Periera, vice president of patient advocacy, Saniona

- Stakeholder Mapping And
   Environmental Assessments
- Creating Shared Objectives
- Early Engagement Opportunities





# Stakeholder Mapping And Environmental Assessments – Intelligence Gathering

- Education and Awareness
- Advocacy
- Research
- Collaborations with Industry



# Creating Shared Objectives

- Putting People First
- Innovation with Impact
- Integrity Always





## Early Engagement Opportunities

- Ask About Their Journey
- Ask About Their Experiences with HME
- Invite the Patient Voice In





# ITEM Coalition (Independence Through Enhancement of Medicare and Medicaid Coalition)



ITEM Coalition members include a diverse set of national disability organizations, aging organizations, consumer groups, voluntary health associations, and non-profit provider associations. Membership in the ITEM Coalition is open to all consumer and non-profit provider organizations without any requirement to contribute financially.



#### **Item Partnership in Action:**

- ITEM Letter to Congressional Leadership: <u>ITEM Coalition Letter to House and Senate Leadership in Support of Legislation</u> to Address Significant Medicare Cuts to Durable Medical Equipment Reimbursement. 37 ITEM Members signed on.
- ITEM Coalition Thank You Letter: <u>ITEM Thank You Letter to House Offices for Supporting Intermittent Catheter Coding</u>
   <u>Reform</u>. 25 ITEM Coalition Members signed on.
- Letter to CMS: <u>ITEM Coalition Letter to CMS re Opening the Pending National Coverage Analysis for Standing Systems in Group 3 Power Wheelchairs</u>. 69 ITEM Coalition Members and additional supporting organizations signed on.
- ITEM Policy Recommendations: <u>ITEM Coalition Wheelchair Repairs and Maintenance Policy Recommendations</u>. 41 ITEM members signed on.
- Letter to CMS: <u>ITEM Coalition Letter to CMS re Medicare Coverage for Transanal Irrigation (TAI) Device Coverage</u>. 18 ITEM
   Coalition Members signed on.



### Our mission is to make ALS livable and cure it.

- We are the world's leading ALS organization, made up of volunteers who are living with ALS, loved ones, caregivers, advocates, and dedicated staff. Our goal is to make ALS livable for everyone, everywhere, until we can cure it.
- On the ground in all 50 states, we are providing support for people living with ALS and their loved ones while funding the most promising ALS research in the world. We are also leading local and national advocacy efforts to deliver more funding for ALS research and better policies for those impacted by the disease.
- Our commitment is that every person living with ALS, regardless of where they live, should be able to access high-quality care and effective treatments.





#### **ALS Partnership in Action**

BLOG POST from the ALS ASSOCIATION

Noninvasive Ventilators are not a Luxury, but a Lifeline for People Living with ALS



- Letters sent to MA payers regarding authorization practices limiting access to NIV
- Collaborative meetings with CMS Part C Oversight regarding NIV concerns
- Collaborative effort to gather personal stories from NIV users living with ALS
- ALS Association support with state legislative efforts – elimination of step therapy requirements for NIV

https://www.als.org/blog/noninvasive-ventilators-are-not-luxury-lifeline-people-living-als





#### Collaboration...

We have collaborated with United Spinal on several issues including state legislation mandating coverage for complex rehabilitation technology (CRT) products under Medicaid for people residing in a nursing facility.



https://unitedspinal.org/



#### **Ostomy White Paper Collaboration**



















#### The Critical Need to Provide Ostomy Supplies Specific to Patient Need to Improve Health Outcomes

#### **EXECUTIVE SUMMARY**

An estimated 725,000-1,000,000 individuals in the United States are currently living with an ostomy. An ostomy is a surgical advancement that has enhanced the ability to treat disease or repair and minimize the effects of trauma. Ostomy surgery involves creating a stoma (opening) in the gastrointestinal tract or within the urinary system to divert stool or urine. Each body and ostomy type is unique, and a customized approach is required in order to determine the combination of products and brands that best meet a person's clinical and personal needs. Ostomy supplies and services such as education and delivery are provided by Home Medical Equipment (HME) providers to help individuals manage their ostomy needs in the home setting.

Life-sustaining ostomy surgeries have a significant impact on mortality, health outcomes, quality of life, and end users' ability to continue contributing to the economy. HME providers play a key role in creating successful outcomes for end users with ostomies, allowing them to regain many aspects of their pre-surgery life. These providers/suppliers are an essential part of the continuum of care and work closely with the clinical community to deliver appropriate supplies to people living with an ostomy that is affordable to the insurance provider and patient.

Recent payer trends in the Medicaid, private insurance, and Managed Care Organizations (MCO) markets have made it more challenging for the HME provider community to provide the ostomy supplies and services that meet clinical and personal needs of individuals. Unsustainable reimbursement rate reductions limit both the services provided and the types and brands of ostomy supplies offered. This can lead to avoidable hospital readmissions, restriction of end users' choice, product access, and access to care. HCPCS (Healthcare Common Procedure Coding System) reimbursement for ostomy appliances has been trending downward against research and development costs, causing increased associated costs for the end user. Collectively, these restrictions ultimately add risk for adverse health outcomes that affect the total cost of care and cause inequity in access to care.

This paper is the second of a white paper series to address the type of products and HME provider services needed to manage an individual's bowel and bladder needs and how ensuring adequate reimbursement for these supplies is an indispensable part of payers achieving the Triple Aim of health care, as stated by the Institute of Healthcare Improvement as improving the patient experience and health outcomes while reducing costs. To ensure end users receive the appropriate products and to promote the most positive outcomes, payers need to ensure rates for these services are no less than the current corresponding 2021 Medicare fee for service rates for these products.

#### ABOUT OSTOMY

#### Ostomy Overview

People living with an ostomy have had surgery that requires removal of their bladder and/or removal or bypass surgery in areas within the gastrointestinal tract, which impairs their ability to store and eliminate bodily waste. They have a surgically-created stoma (opening) for diversion of the gastrointestinal or urinary tract for elimination of waste. Ostomy supplies are defined as prosthetic devices under the Social Security Act; they replace the lost function of waste, storage, and elimination.<sup>3</sup>

The ostomy pouching system is self-applied or applied by a caregiver, worn continuously, emptied of waste as needed, and changed as needed. Ostomy prosthetic devices are unique to each individual's body profile

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American Association for Homecare

#### **Urological White Paper Collaboration**



















#### The Critical Need to Provide Intermittent Catheter Urological Supplies Specific to Patient Need to Improve Health Outcomes

#### EXECUTIVE SUMMARY/PURPOSE

Individuals with urinary retention may require assistance draining their bladder via catheters inserted into the urethra. Home medical equipment (HME) providers work closely with the end user and clinical community to provide urological supplies and services to those requiring catheterization in a home-based setting. While there are many different types of catheters to meet individual's needs, this paper will primarily focus on intermittent catheterization.

Depending on one's clinical needs, a variety of urological supplies are available to help manage one's medical condition, increase adherence, and prevent negative health outcomes such as catheter-associated urinary tract infections (CAUTIs) which can exacerbate co-morbidities and increase costs of care. Intermittent catheters, which are used to drain the bladder at certain intervals throughout the day, do not remain inserted into the bladder. They are the preferred method of bladder management among individuals with urinary retention and are clinically shown to have a lower risk of CAUTI. In addition to providing supplies, HME providers and their manufacturer partners provide extensive education and support for those using urological supplies to maximize outcomes and empower the end user to self-catheterize safely and effectively.

Declining reimbursement trends in the Medicaid, private insurance, and Managed Care Organizations (MCO) markets have made it more challenging for the HME provider community to provide the urological supplies and services that meet clinical and personal needs of individuals. Current Medicare codes for intermittent catheters are fairly generic and do not distinguish the wide range of products with differing features classified within a single Healthcare Common Procedure Coding System (HCPCS) code. Unsustainable reimbursement rate reductions limit both the services provided and the types and brands of urological supplies offered. This can lead to avoidable restriction of end users' choice, product access, and access to care, as well as hospital readmissions ultimately increasing the total cost of caring for individuals requiring catherization.

This paper is the third of a white paper series to address the type of products and HME provider services needed to manage an individual's bowel and bladder needs. The series also highlights how ensuring adequate reimbursement for these supplies is an indispensable part of payers achieving the Triple Aim of health care, as stated by the Institute of Healthcare Improvement as improving the patient experience and health outcomes while reducing costs. To ensure end users receive the appropriate products and to promote the most positive outcomes, payers need to ensure rates for these services are at appropriate levels.

#### UROLOGICALS OVERVIEW

Catheters are used to drain the bladder when an individual cannot control the process of urination or is unable to empty their bladder. A catheter is a thin, hollow tube inserted into the urethra or inserted into surgically created stomas/Mitrofanoff valve to drain the bladder into a drainage bag or toilet. There are many varieties of catheters available depending on an individual's unique medical needs.

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### **Incontinence White Paper Collaboration**







NATIONAL ASSOCIATION FOR CONTINENCE









#### Keeping Patients at Home with Improved Outcomes Through the Use of Quality Incontinence Products and HME Providers

#### INTRODUCTION

Incontinence, also known as the loss of bladder or bowel control, is a common problem among older adults as well as people with disabilities. Urinary incontinence can lead to unwarranted physical, psychosocial, and economic burdens on both the patient and their caregivers. This is the first of a two-part white paper series to address the types of products and services needed to successfully manage an individual's incontinence needs; the next paper will address the use of ostomy and urology products.

Annual costs of managing and treating incontinence in the United States is estimated to cost \$65.9 billion, with \$51.4 billion directly related to medical care, such as medical treatments/procedures, supplies, medication, hospitalization, long-term care stays, physician visits, and laboratory tests (Coyne KS, 2014). Failure to properly manage incontinence results in medical complications including incontinence-associated dermatitis (a known precursor to ulcers and pressure injuries), urinary tract infections, falls, and psycho-social issues.

Home Medical Equipment (HME) providers who provide incontinence products and services are critical to patient (end user) care and cost management. They work with the prescribing health care provider and end user to properly manage the individual's incontinence needs by matching the person with the appropriate product(s) to ensure proper fit and size and providing essential services and ongoing monthly support in a cost-effective homecare setting. To optimize end user experience and outcomes while decreasing utilization and the overall cost of care, HME providers use high quality products that meet or exceed the National Association for Continence (NAFC) premium standards.

However, recent payer trends in the Medicaid and MCO market have challenged the HME provider community. Unsustainable rate reductions prevent HME providers from being able to provide premium products, as well as products that meet the patient need and optimize self care, and provide services such as monthly consultations with the end user/caregiver to manage incontinence. Without these premium products and services, the total cost of care increases significantly while patient outcomes and satisfaction deteriorates.

By ensuring adequate reimbursement for quality products by reputable HME providers, payers can achieve the triple aim of improving the end user's experience and quality of life, creating better health outcomes, and reducing the overall cost of care.

#### **OVERVIEW OF INCONTINENCE**

#### People with Incontinence

51% of females and 21% of males deal with incontinence at some point after 65 years of age. Females are 1.7 times more likely than males to become incontinent during their life span (Gorina, 2014).

Studies estimate that bladder incontinence alone costs \$20 billion dollars annually (American College of Chest Physicians, 2014). In addition to the cost associated with products and services needed to manage an incontinent condition, many complications and added costs can be attributed to daily management. Adults who suffer from incontinence also have a high risk of falls, UTIs, and complications with skin breakdown due to being in contact with the high acidity of urine and or stool (Health Economics Resource Center, Department of Veterans Affairs, Sanford University School of Medicine, 2002). Incontinence also affects sleep quality, which

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# **Next Steps**

- Identify
- Strategize
- Execute Your Action Plan



### **CONTINUE TO SUPPORT YOUR STATE ASSOCIATION!**



















Thank you for being a sponsor of the AAHomecare Payer Relations team

INVESTING IN
PAYER RELATIONS
ADVOCACY
EFFORTS





### **AAHomecare Needs You**

- AAHomecare needs members to meet the challenges ahead. All dues to AAHomecare directly support lobbying, research, and public awareness efforts that are part of our advocacy program.
- To join, contact Michael Nicol, Senior Director of Membership Services: <u>michaeln@aahomecare.org</u> or 410-299-7100.





### **THANK YOU!**

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**LET'S CONNECT** 



CONSULTATION