



Psychological, Physical, and Financial Challenges of Receiving a Hereditary Angioedema (HAE) Diagnosis

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INTRODUCTION

Hereditary Angioedema (HAE) is a rare genetic disorder characterized by unpredictable and potentially life-threatening swelling attacks, often in the hands, feet, face, gastrointestinal tract, or airway. Living with HAE brings a myriad of challenges that extend far beyond physical symptoms, impacting emotional well-being and finances. For those diagnosed with HAE, the journey to manage the disease is often marked by complex psychological, physical, and financial burdens. This article explores the multifaceted impact of an HAE diagnosis, shedding light on the need for comprehensive support systems to help patients and their families navigate these challenges.

DESCRIPTION

Psychological burden of an HAE diagnosis

The emotional toll of an HAE diagnosis is significant. The unpredictable nature of HAE attacks creates a constant sense of uncertainty, leading to heightened levels of anxiety. Individuals with HAE often worry about the timing, severity, and location of the next attack, particularly because some episodes such as those affecting the airway can be fatal if not treated immediately.

Fear and anxiety: The potential for airway obstruction during an attack induces intense fear and anxiety, not only in patients but also in their families. For many, each new episode brings fresh worries about their ability to reach medical help in time, adding to the stress of daily life. This persistent fear can interfere with regular activities, making patients reluctant to travel, socialize, or engage in activities where immediate help may not be accessible.

Depression and isolation: Living with a chronic, unpredictable condition like HAE can lead to depression. Patients may feel isolated, especially if they believe that those around them cannot fully understand the complexity of the disease. This isolation is worsened by the physical limitations imposed by frequent or severe attacks, which may lead individuals to withdraw from social and work activities. The burden of explaining HAE to

others can also be exhausting, causing some patients to hide their condition, further deepening their sense of isolation.

Impact on relationships: The strain of managing HAE can take a toll on personal relationships. Family members may become caregivers, which can alter the dynamics within families and add stress for everyone involved. Partners may also struggle with the psychological and logistical challenges of caring for someone with a potentially life-threatening condition, impacting their mental health and, at times, the stability of the relationship.

Physical burden of HAE

The physical symptoms of HAE vary, but they are often painful and debilitating. Swelling episodes may occur in various parts of the body, each with distinct symptoms and challenges.

Pain and physical discomfort: Swelling in the extremities, abdomen, or face can be intensely painful. Abdominal attacks, for example, may cause severe, cramping pain and lead to nausea, vomiting, and dehydration. Attacks in the extremities can impair mobility, leaving patients unable to perform even basic tasks. Swelling of the face, lips, or throat can be particularly distressing, as it not only causes pain but also poses a life-threatening risk if the airway becomes obstructed.

Physical limitations: Recurrent HAE episodes can limit patients' ability to work, exercise, or pursue hobbies. Some individuals may need to avoid activities that could trigger an attack, such as heavy physical exertion or emotional stress. This restriction can further impact their quality of life, leading to decreased physical fitness, loss of strength, and an overall reduction in well-being.

Chronic health complications: Long-term physical effects can result from frequent HAE attacks and the medications used to manage them. Some treatments, particularly older therapies, may have side effects that contribute to weight gain, high blood pressure, or other health issues. The physical burden of HAE is therefore not limited to acute episodes but includes the cumulative impact of ongoing symptoms and treatment side effects.

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Financial burden of HAE

The financial implications of an HAE diagnosis are substantial and often lifelong. Between the cost of treatments, emergency visits, and the indirect costs associated with lost productivity, managing HAE can place a heavy financial strain on patients and their families.

Cost of treatment: HAE treatments are costly, particularly newer, more effective options. Prophylactic treatments to prevent attacks can be expensive, and on-demand therapies for acute attacks also carry high costs. For some families, covering these expenses may mean facing substantial out-of-pocket costs, even with insurance. For those without adequate coverage, the financial burden can be overwhelming.

Frequent medical visits and emergency care: Because HAE attacks can be life-threatening, patients often require urgent medical care. Frequent emergency visits add to healthcare costs, as do regular check-ups with specialists to manage the condition. Travel expenses, time away from work, and other indirect costs further contribute to the financial burden.

Employment and income impact: The physical and psychological toll of HAE often affects patients' ability to work

consistently. Many individuals with HAE may need to take time off work for medical appointments or due to the debilitating nature of attacks. This may reduce income, hinder career progression, and even lead to job loss. Furthermore, employers may struggle to accommodate the unpredictability of HAE-related absences, placing additional strain on patients' job security and financial stability.

CONCLUSION

A diagnosis of hereditary angioedema presents significant psychological, physical, and financial burdens. The unpredictable and chronic nature of HAE exacerbates anxiety and depression, impacts physical capabilities, and creates financial strain due to high treatment costs and potential loss of income. Given the complexity of these challenges, HAE patients require a multidisciplinary approach that includes psychological support, patient education, financial guidance, and access to specialized care. By addressing the multifaceted impacts of HAE, healthcare providers, patient advocates, and support networks can help improve the quality of life for those affected by this rare but severe condition.