

# IMPACT OF HAE ON MENTAL HEALTH

HAE results in a high burden for those affected due to the chronic nature of the disease, severity of symptoms, time lost from work/school, and disruptions in social interactions and relationships. Recognition of the impact of HAE on mental health is an unmet need for many of those affected but is critical for optimal individualized care. In this article, we will describe the complex relationship between HAE, mental health, and quality of life.



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## HAE attacks are unpredictable, with many triggers

For reasons that are not well understood, HAE attacks are unpredictable with a variety of possible symptoms and variable severity. Most HAE attacks occur spontaneously. However, attacks may also be triggered by a number of factors, including:

- Stress
- Anxiety
- Physical trauma/injury
- Medical or dental procedures
- Infection
- Pregnancy
- Menstrual cycle
- Medications, such as the oral contraceptive, hormone replacement therapy, and ACE inhibitors

## HAE attacks can be painful and potentially life-threatening

HAE attacks can be painful, debilitating, disfiguring, and affect most body areas, including the throat, lips, face, abdomen, and limbs. Of particular concern are throat attacks which may become life-threatening and abdominal attacks which may be mistaken for conditions that require urgent surgical treatment.



## The daily lives of patients and caregivers are impacted by HAE

Symptoms commonly experienced during an HAE attack, including abdominal pain, bloating, vomiting, diarrhea, and disfiguring swelling, can prevent patients from performing daily tasks.

- Patients may lose between 20 and 100 days of social activities each year due to HAE.
- Family caregivers worry about the patient and feel that the situation is out of their control.
- Many HAE patients require assistance during an attack, so families and caregivers also share the disease burden.
- Both patients and caregivers experience increased time lost from work and school with increased attack frequency and severity.



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## Anxiety and depression are both a trigger and a consequence of HAE

Anxiety and depression can not only trigger HAE attacks, but patients living with HAE may experience psychological distress presenting as anxiety and depression. The interaction between psychological distress and HAE creates a vicious cycle which will result in more HAE attacks and more stress.

- Studies have found that depression and anxiety occur in  $\leq 70\%$  and  $\sim 50\%$  of HAE patients, respectively.
- Patients with more severe HAE have higher levels of anxiety and depression.
- There is also a gender difference with females reporting greater stress, fears, and lower quality of life with HAE.



## Stress and a decreased ability to regulate and process emotions may increase HAE impact in children

Emotional stress has been reported by HAE patients as the most common trigger factor for HAE attacks. Perceived stress appears to be worse in children with HAE compared with children with other chronic diseases.

Difficulties regulating and processing emotions is referred to as alexithymia, a concept that is particularly important when living with HAE. The inability to identify and describe feelings may result in reduced abilities to cope with stress.

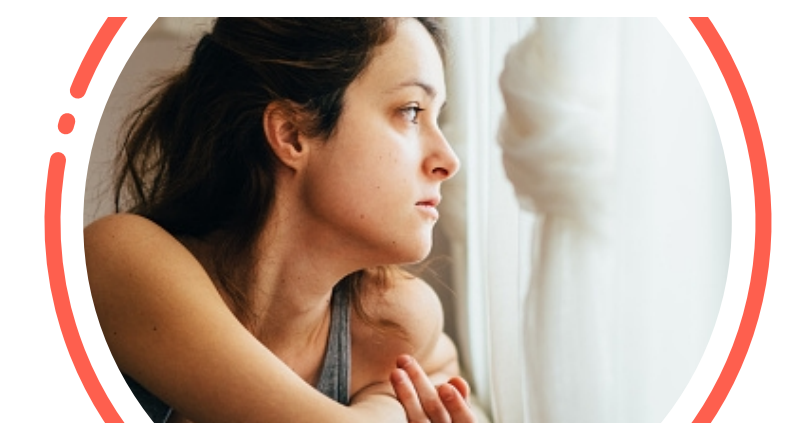
Alexithymia is common in children with chronic diseases. In HAE, it may result in increased perceived stress and act as a trigger of HAE attacks. Alexithymia has also been associated with more severe disease.

## Opportunities may be missed due to the unpredictability of HAE

The unpredictable nature of HAE may cause individuals to avoid traveling, limit hobbies, minimize social opportunities, and impact personal relationships.

## Life decisions may be impacted by HAE

HAE may have a significant impact on life decisions and events. For example, patients may have anxiety about having children. A survey identified the potential transmission of HAE to children, fear of sudden airway closure, and severe pain among the greatest concerns for those living with HAE.





## Sleep may be affected by HAE

The effect of HAE on sleep has not been well studied. However, sleep disturbance was reported in 76.5% of HAE patients who participated in a recent study. It has been suggested that sleep may be negatively impacted by HAE attacks starting or evolving during the night or it may be due to worry and anxiety that can occur when living with HAE.



## Education and career opportunities may be lost due to HAE

HAE may negatively impact career and personal development because of the unpredictable and disruptive nature of attacks. A study published in 2010 found that patients lost, on average, 3.3 days from work and 1.9 days from school during an HAE attack.

HAE can also influence the direction of education and/or career with 40% indicating that HAE had prevented them from going as far in school as they would have liked and 69% not able to consider certain jobs because of HAE.

Surveys of HAE patients in Europe and the US have described that 36–57.5% of respondents reported limitations in career advancement and 42–48.4% reported lower educational achievement.

## Strategies to improve mental health

Incorporating psychological support is a requirement for comprehensive care given the close relationship between mental well-being and physical symptoms of HAE. Strategies to improve mental health include:

- Develop a support network. Seek support from family, friends, and HAE patient organizations. Share information and experiences to improve knowledge, emotional processing, and empowerment.
- Use a healthy diet and exercise to improve physical and mental health.
- Use yoga, meditation, and mindfulness techniques to calm the mind, and improve emotional regulation and coping.
- Improve sleep hygiene to reduce sleep disturbance and fatigue.
- Recognize and eliminate triggers and unhealthy behaviours to reduce HAE attacks.
- Improve HAE symptom control using targeted HAE-specific therapies, home infusion programs, and long-term prophylaxis when appropriate.
- Good communication with healthcare providers will ensure that your mental health is regularly assessed and concerns are being addressed appropriately. Patients may benefit from referrals to mental health professionals, including counsellors, psychologists, or psychiatrists, or medication to improve mental health.

If you or your loved one is experiencing any of the mental health issues outlined in this article, reach out to your healthcare team. They will work with you to determine strategies to improve your mental well-being and quality of life.

