

## In Their Own Words - Patient Descriptions of the Earliest Recognition of Hereditary Angioedema (HAE) Attack Onset

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## Background

- Hereditary angioedema (HAE) is a genetic disease resulting in deficiency (type I) or dysfunction (type II) in the complement-1 esterase inhibitor (C1-INH) protein and subsequent uncontrolled activation of the kallikrein-kinin system (KKS).
- People living with HAE experience painful and debilitating attacks of tissue swelling in various locations of the body that can be life-threatening depending on the location affected.
- Symptoms of an HAE attack can potentially interfere with the ability to conduct daily activities (work, school, social activities)<sup>1</sup>
- Initial HAE attack onset can be highly individualized, underscoring the complex nature of how these attacks manifest.

# Objective

- The objective of this survey was to characterize the way people living with HAE recognize and describe the onset of an attack

## Methods

- People living with HAE were recruited by the US Hereditary Angioedema Association (HAEA) to complete an online survey
- The survey was self-reported, and took respondents approximately 20 minutes to complete
- The survey was completed by 107 individuals between September 6 and October 19, 2022; response rate 69% (107/155)
- Respondents provided consent for their data to be used anonymously or in aggregate
- Analysis was performed using descriptive statistics

## References

1. Bygum A. Hereditary angioedema—consequences of a new treatment paradigm in Denmark. *Acta Derm Venereol*. 2014;94(4):436–41.

## Disclosures

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## Results

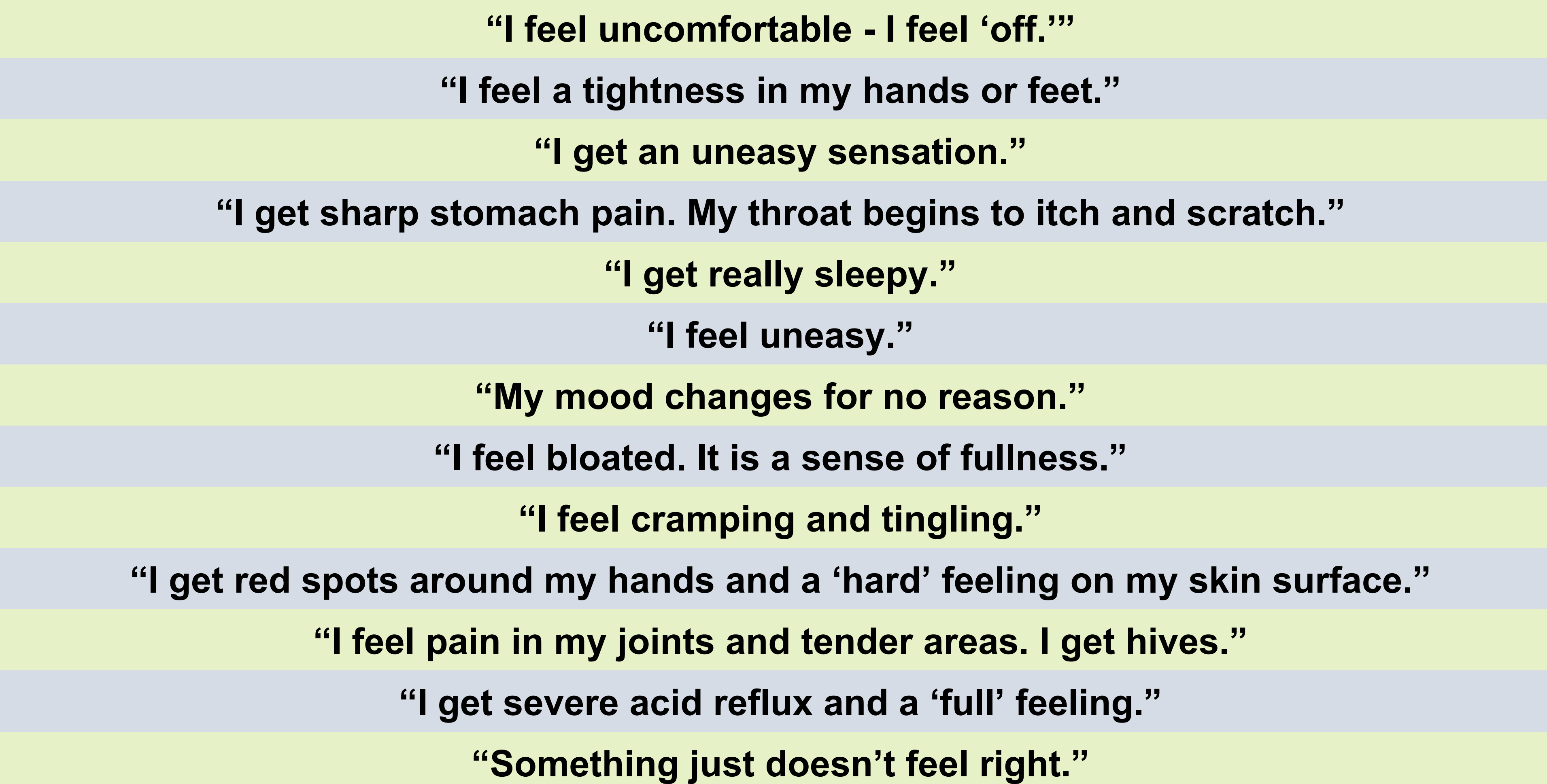
### Figure 2. Words Used by Respondents to Describe When an HAE Attack has Started



### Figure 3. Common Themes of Words Used to Describe HAE Attack Onset



### Table 2. Statements Used by Respondents to Describe the Onset of an HAE Attack



## Conclusions

- **Survey results highlighted that the descriptions used by people living with HAE to describe attack onset are variable and highly individualized**
- **People living with HAE are able to consistently recognize and describe the initial onset of an HAE attack**
- **Additional studies are needed to explore if these findings align with patient behaviors when treating HAE attacks**
- **These findings may help to inform future treatment discussions and may enhance aspects of the physician/patient dialogue**

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