

# FINNISH HAE PATIENTS' EXPERIENCES OF QUALITY OF LIFE – A SURVEY

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## INTRODUCTION AND SUMMARY

There are approximately 100 – 150 Hereditary Angioedema (HAE) patients in Finland. The Finnish HAE Association has 79 members, and it is a member association of the Finnish Allergy, Skin and Asthma Federation. Federation has 54 member associations with appr. 18 500 individual members.

The most characteristic signs and symptoms of HAE are recurrent attacks of severe swelling. The severity of the attacks vary individually. At worst the attacks can be lethal in case no proper medicine is available.

The aim of the survey was to acquire more knowledge of the impact of HAE on patients' quality of life. Another aim was to develop the services and support provided for the HAE patients.

The results reveal that the needs for support of HAE patients vary a lot according to the severity of the symptoms, and more detailed information is needed to better improve the services provided for them.

## METHODS

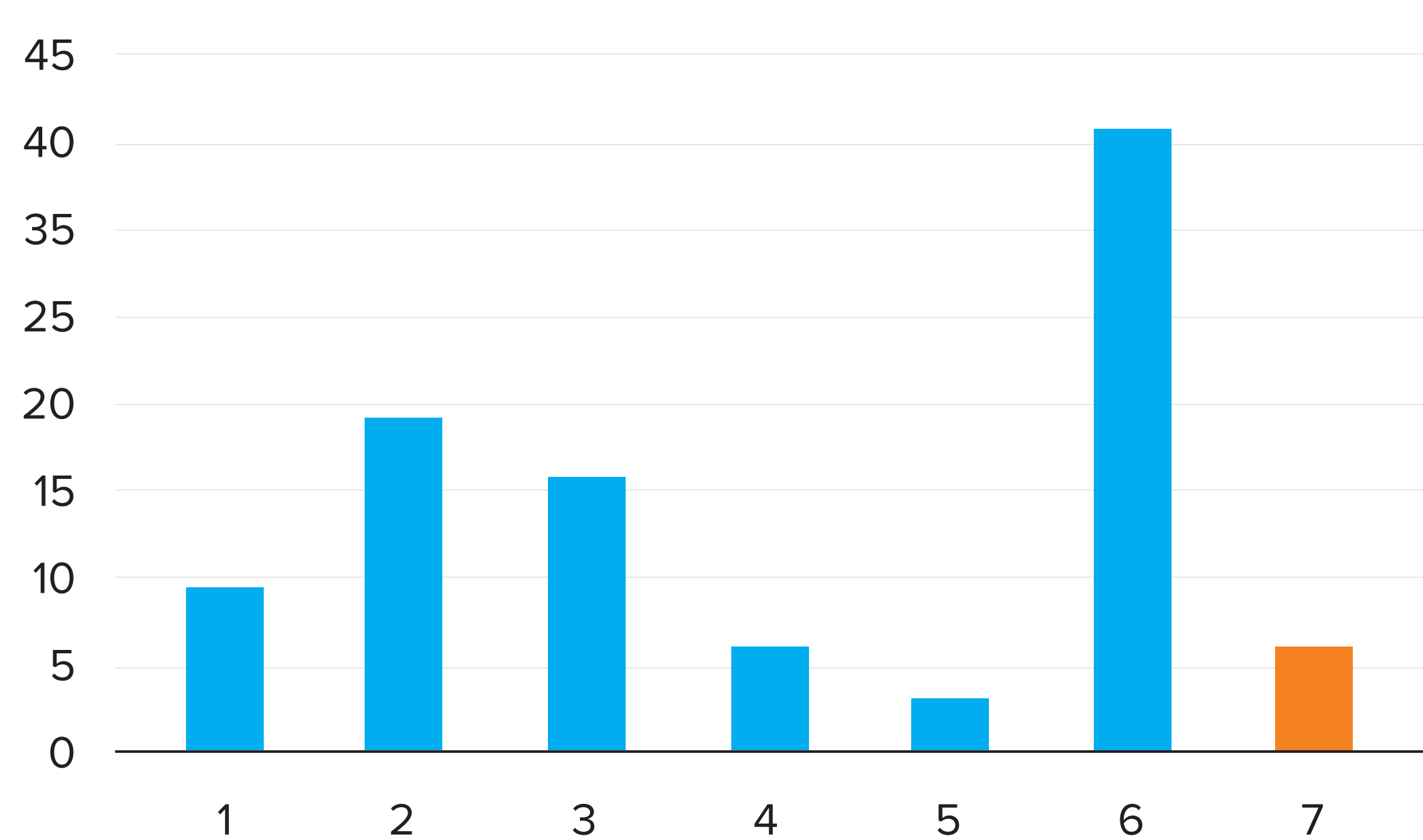
A SurveyPal survey was conducted in 2017 (n=32). All the members of Finnish HAE Association received either a link to the survey or a print of the survey by mail. A further survey was conducted in 2018 to specify the results of the first survey (n=22). There is no sex predominance in HAE. Still most of the respondents were women due to high percentage of women members in the association. Almost 70 % of the respondents were still active in working life.

## RESULTS

### Diagnosis

Typically for a rare disease, almost half of the respondents had waited for the diagnosis over eight years after the first symptoms and doubts. During the process many patients experienced negative attitudes and lack of support. Many of the respondents claimed that health care professionals' lack of knowledge was the main reason for this.

Chart 1. How long time did you wait for the diagnosis after first symptoms?



1 = less than a year, 6 = more than 8 years, 7 = don't know

The survey results reveal that the impact of HAE on patients' life varies a lot. Almost half of the respondents evaluated their quality of life poor or really poor. On the other hand almost half of them found the impact of their disease very low or non-existent.

*"I have learned to live with HAE"*

*"I have HAE attacks every month but luckily I have the right medicine"*

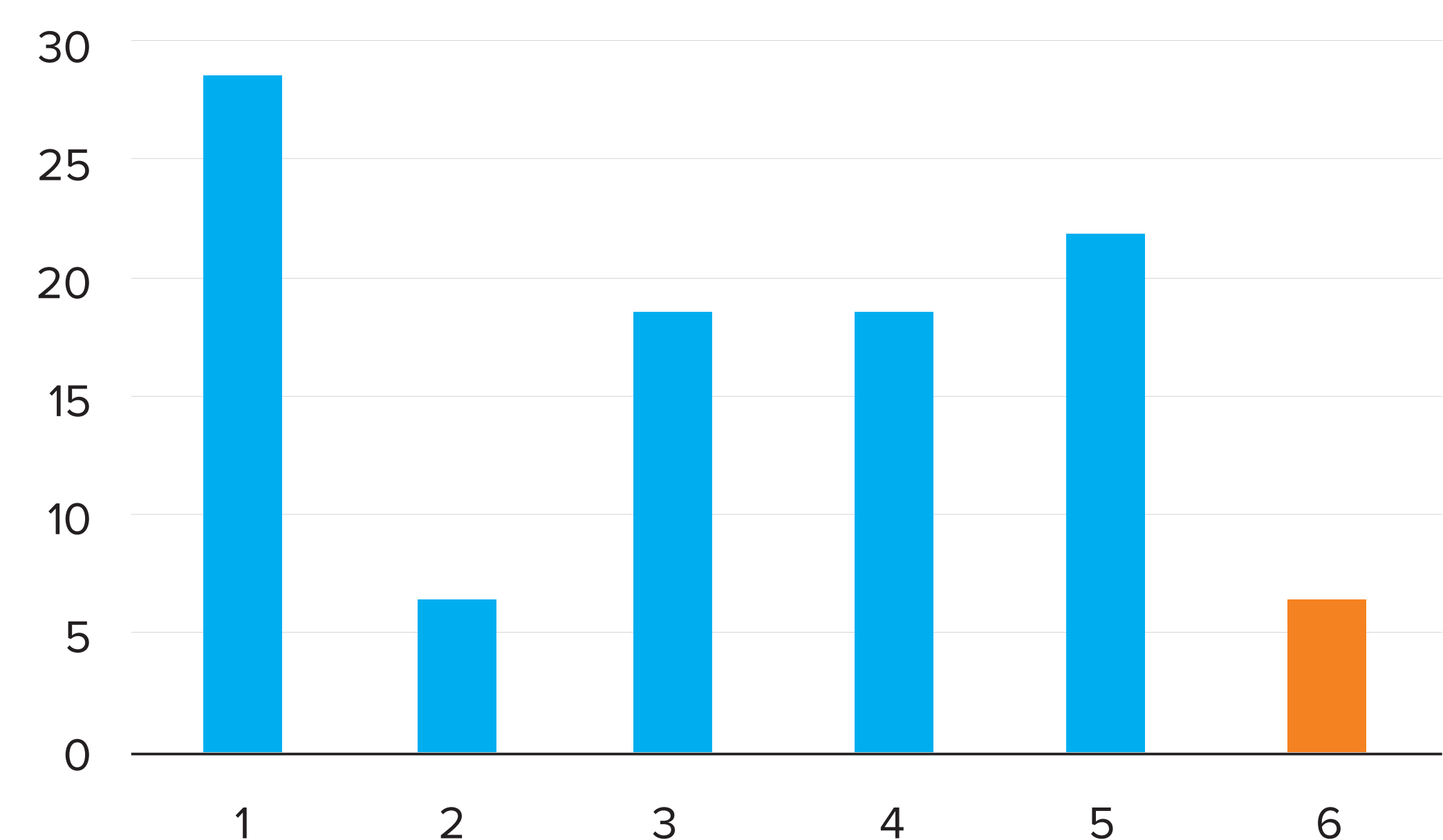
### The impact on functionality and occupational life

During the last five years over half of the respondents have experienced a lot of individual variation in functionality. Over 40 % of the respondents estimate the negative impact of HAE being high as 20 % estimate it being low. The respondents described how the non-predictable nature of attacks made their life difficult. All this had negative influence for example on occupational life. Over half of the respondents claimed that HAE had affected their working career a lot or very much. Also prejudices from the part of co-workers and employers are commonly reported in the open-ended questions.

### The importance of the relatives and friends

The role of the relatives and friends as caregivers was important for over half of the respondents. Their role was especially important in helping HAE patients to take the medication. The non-predictable and possibly lethal nature of attacks caused stress both to HAE patients and relatives. 40 % of the HAE patients estimate the negative impact of their disease being strong or very strong on their relatives.

Chart 2. The impact of HAE on relatives



1 = low impact, 5 = strong impact, 6 = don't know

Further, almost 40 % of the respondents evaluated that HAE had reduced and restricted their social life a lot or very much. Many of the respondents comment that with the help of medicine the quality of social life has improved. Almost 80 % of the patients estimate the medicine effective or very effective.

*"A sick person is not accepted among the healthy ones"*

*"I lost all my friends as I had the worst experiences with the disease"*

### Social services and official support

Almost 80 % of the respondents have their follow-up organized in specialized health care units (university or central hospitals). Still, most of the respondents have never met hospital's social worker or rehabilitation advisor. Everyone was familiar with medical expenses reimbursement, but other social benefits and services are known only to some of the respondents.

*"No-one has ever told me about these things"*

*"It is so frustrating to fight for your rights"*

## CONCLUSIONS

The results of the surveys are in line with the earlier studies. For some patients the quality of life is severely affected by HAE. Health care professionals should pay more attention to the impacts of HAE on everyday life. Social workers should always be involved when evaluating patients' needs for support. Also the role of relatives should better be taken into consideration in order to ensure the needed support.

The Federation should concentrate more on informing health care professionals about the extreme impacts of HAE in patients' life. Also the co-operation with health and social care professionals should be enforced, especially with the HAE specialists and the Finnish ERN Skin Center for Rare and Undiagnosed Skin Diseases in Helsinki University Hospital. The results of survey are taken into account as the services of the Allergy, Skin and Asthma Federation are being developed.