

ANGIOEDEMA CONTROL TEST (AECT)

Patient name: _____

Date: _____

Date of birth: _____

Instructions: You have recurrent swelling referred to as angioedema. Angioedema is a temporary swelling of the skin or mucous membranes which can occur in any part of the body but most commonly involves the lips, eyes, tongue, hands, and feet and which can last from hours to days.

Some patients develop abdominal angioedema, which is often not visible but painful.
Some forms of swelling can also be associated with hives also known as urticaria.

For each question, please choose the answer from the five options that best fits your situation.
Please answer all questions and please provide only one answer to each question.

1. In the last 3 months, how often have you had angioedema?

<input type="checkbox"/> very often	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> seldom	<input type="checkbox"/> not at all
0	1	2	3	4

2. In the last 3 months, how much has your quality of life been affected by angioedema?

<input type="checkbox"/> very much	<input type="checkbox"/> much	<input type="checkbox"/> somewhat	<input type="checkbox"/> a little	<input type="checkbox"/> not at all
0	1	2	3	4

3. In the last 3 months, how much has the unpredictability of your angioedema bothered you?

<input type="checkbox"/> very much	<input type="checkbox"/> much	<input type="checkbox"/> somewhat	<input type="checkbox"/> a little	<input type="checkbox"/> not at all
0	1	2	3	4

4. In the last 3 months, how well has your angioedema been controlled by your therapy?

<input type="checkbox"/> not at all	<input type="checkbox"/> a little	<input type="checkbox"/> somewhat	<input type="checkbox"/> well	<input type="checkbox"/> very well
0	1	2	3	4

Adaptation of the AECT questionnaire by Weller et al.

The 5 answer options of each AECT item are scored with 0 to 4 points.
The AECT score is calculated by **summing up all 4 item scores**, with a minimum and maximum **possible score of 0 to 16 points**, and with higher scores indicating a higher level of angioedema control.

The AECT can help your doctor determine if you have **poorly controlled recurrent angioedema (0 to 9 points)** to **well-controlled disease (10 to 16 points)**.

Total Score _____

References:

1. Weller K, Donoso T, Magerl M, et al. Development of the Angioedema Control Test—A patient-reported outcome measure that assesses disease control in patients with recurrent angioedema. *Allergy* 2019;00:1–12.
2. Weller K, Donoso T, Magerl M, et al. Validation of the Angioedema Control Test (AECT)—A patient-reported outcome instrument for assessing angioedema control. *J Allergy Clin Immunol Pract* 2020 Mar 12. pii: S2213-2198(20)30239-7.



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ANGIOEDEMA QUALITY OF LIFE QUESTIONNAIRE (AE-QoL)

Family name of person filling out form: _____

Given name: _____

Date of birth: _____

Date questionnaire filled out: _____

Instructions: In the following questionnaire, you will find a series of questions. Please read each question and from the five possible responses, select the one that best applies to you. Please remember to answer all questions and to give only one answer for each question, i.e., check only one box per question.

Specify how often, over the past 4 weeks , the recurring swelling (angioedema) has restricted you in the following areas of daily life. (It is not necessary for swelling to have actually occurred during this time.)	Never	Rarely	Occasionally	Often	Very often
1. Work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Physical activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Leisure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Social relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The following questions focus in more detail on the difficulties and problems that can be associated with your recurring swelling (angioedema) regarding the last 4 weeks .	Never	Rarely	Occasionally	Often	Very often
6. Do you have difficulty falling asleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you wake up at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are you tired during the day because you don't sleep well at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you have trouble concentrating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ANGIOEDEMA QUALITY OF LIFE QUESTIONNAIRE (AE-QoL)

The following questions focus in more detail on the difficulties and problems that can be associated with your recurring swelling (angioedema) regarding the last 3 months.	Never	Rarely	Occasionally	Often	Very often
10. Do you feel depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you have to restrict your choices of food or drink?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Is the swelling, which occurs on your body due to the disease, a burden to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Are you afraid some swelling might occur suddenly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Are you afraid the frequency of the swelling could increase?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Are you ashamed to go to public places due to the recurring swelling?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Are you embarrassed or self-conscious due to the recurring swelling?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Are you afraid that the treatment of the recurrent swelling could have long-term negative consequences for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Domain Scores Functioning _____ Fatigue/Mood _____ Fears/Shame _____ Nutrition _____	Total Score _____
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See page 3 for complete calculation instructions.

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Reference:

Weller K, Groffik A, Magerl M, et al. Development and construct validation of the angioedema quality of life questionnaire. *Allergy* 2012 Oct;67(10):1289-98.



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