

Supplement 1. Translated questionnaire.

PATIENT ID: DATE: INVESTIGATOR ID:

TEST WITH: the patient him/herself patient with some assistance of the carer the carer with the patient 's participation the guardian only

METHOD: in person by phone via the Internet traditional correspondence

M. DEMOGRAPHIC QUESTIONS

<p>M.1. Age</p> <ul style="list-style-type: none"> <input type="radio"/> 18-29 <input type="radio"/> 30-39 <input type="radio"/> 40-49 <input type="radio"/> 50-59 <input type="radio"/> 60-69 <input type="radio"/> 70 years or more 	<p>M.3. Location</p> <ul style="list-style-type: none"> <input type="radio"/> Rural area <input type="radio"/> city up to 50,000 residents <input type="radio"/> city up to 100,000 residents <input type="radio"/> city up to 250,000 residents <input type="radio"/> a city with over 250,000 residents
<p>M.2. Sex</p> <ul style="list-style-type: none"> <input type="radio"/> woman <input type="radio"/> man 	<p>M.4. Education</p> <ul style="list-style-type: none"> <input type="radio"/> elementary <input type="radio"/> junior high school <input type="radio"/> high school <input type="radio"/> higher

A. DIAGNOSTIC PATH

<p>A.1.1. When did the first symptoms occur?</p> <p>A.1.2. Description of symptoms:</p>	
<p>A.2.1. When was first diagnosis established (any diagnosis, not necessarily the correct one)?</p> <p>A.2.2. What was the diagnosis?</p> <p>A.2.3. Where? By whom? (physicians specialty)</p>	
<p>A.3.1. When was subsequent diagnosis established?</p> <p>A.3.2. What was the diagnosis?</p> <p>A.3.3. Where? By whom?</p>	
<p>A.4.1. When was subsequent diagnosis established? (if applicable):</p> <p>A.4.2. What was the diagnosis?</p> <p>A.4.3. Where? By whom?</p>	
<p>A.5.1. When was the final diagnosis established(SLA):</p> <p>A.5.2. Where? By whom?</p> <p>A.5.3. Self-diagnosis:</p>	<p>YES/ NO</p>

(time from first symptoms to final diagnosis: number of incorrect diagnoses)

B. DIAGNOSIS DELIVERY

B.1. Was it suggested that a family member / guardian could participate in the interview?

- Yes
- No
- I don't remember o does not apply (there was such a person)

B.1.1. Do you think it is good to have someone close present during the diagnosis delivery?

- Yes
- No
- I have no opinion

B.2. The conversation took place:

- In the doctor's office
- In the hospital room
- In the hospital corridor / clinic
- Other, what: ...

B.3. Was the diagnosis communicated to you in an understandable way?

- Yes
- No
- Hard to say

B.4. How was the course of the disease / the prospect of living with the disease described to you?

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B.5. Which of the following tests were performed prior to diagnosis:

- EMG
- Magnetic resonance imaging
- Genetic
- Neurological
- Other what

B.6. During the delivery of the diagnosis, did you hear anything that was particularly helpful, uplifting or reassuring?

- Yes Go to question B.6.1.
- No Go to question B.7.
- I don't remember Go to question B.7.

B.6.1. What words and / or behaviors of the doctor (other members of the healthcare team) were particularly supportive, helpful, uplifting or reassuring for you?

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B.7. During the diagnosis, did you hear anything that was unnecessary, inappropriate or soulless?

- Yes Go to question B.7.1.
- No Go to question B.8.
- I don't remember Go to question B.8.

B.7.1. What words and / or behaviors of the doctor (other members of the medical staff) were, in your opinion, unnecessary, inappropriate, soulless?

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B.8 . During the interview during which you were given the diagnosis, did you receive (if any of the following items are indicated, go to B.9., If not go to B.10):

- leaflets / other printed material about the disease
- link to the website of the patients' association / foundation / support group
- contact to patient' association / foundation / support group
- contacting a doctor specializing in ALS treatment (including clinical trials etc.)
- I have not received any material about the disease
- I do not remember
- Other:

B.9. Which materials and sources of information turned out to be particularly helpful in the first months after diagnosis?

- leaflets / other printed material about the disease
- link to the website of the parents' association / foundation / support group
- contact to parents' association / foundation / support group
- contacting a doctor dealing with ALS treatment (including experimental ones)
- I do not remember
- Other:

B.10. What kind of information did you receive during the interview during which the diagnosis was delivered?

- about the mechanism and causes of the disease
- about the treatment options for ALS
- about rehabilitation (physiotherapy, speech therapy, neurological rehabilitation)
- about the options of psychological support
- about the options of social security assistance
- about the domestic ventilation program
- on experimental therapies based on stem cells
- about experimental drug therapies
- on how to deal with the disease in everyday life
- None of the above
- Other:

B.11. In retrospect, do you think that some information that would be helpful was missing?

- Yes (insert below)
 - No Go to question 12.
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B.12. When do you think people with ALS should be informed about their disease:

- only after getting a complete diagnosis
- in a situation where the suspicion of disease is well-grounded
- whenever there is a suspicion of the disease

B.13. Please share any other comments and thoughts on the manner in which you received the diagnosis.

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