

TOPIC GUIDE: INTERVIEW WITH CAREGIVERS OF ALS PATIENTS DURING COVID-19 PANDEMIC

Caregiver profile

- Age, gender
- Past occupation/present occupation and hobbies
- Living situation

Daily routines

- Being a caregiver of a patient with ALS, what did a typical day look like before COVID-19?
- What does a typical day during the COVID-19 pandemic look like? What has changed?

Social network

- Are you part of a community/association/social group?
- With whom did/do you regularly keep in contact?
- What ways of contact do you have? What different communication methods do you use now with your loved ones?
- Many patients and caregivers express a sense of isolation during lockdown. What is your view on that, also considering your condition of caregiver of a patient with ALS?
- When did you decide to self-isolate? How has this self-isolation and physical distancing affected your social networks (i.e. community groups, friends, family)
- Do you regularly get phone calls from family/friends? Has this always been the case, or has it changed since COVID-19?

Vulnerability

- What do you think of the guidelines calling for severely disabling patients to self-isolate?
- Do you feel “vulnerable”?
- What are your views about the media reporting around COVID-19? What about the portrayal of risk attributed to severely disabling people?

Topics important to the participant and satisfaction regarding the telemedicine services offered

- Which topics have we not covered that are important around COVID-19?
- What do you think about our tele-consults/group sessions and individual tele-visits?
- What do you think about our phone calls to monitor remotely ALS patients during lockdown?
- Would you prefer the combination of telemedicine and in-person visits?

Is there anything else you would like to add?