

## Appendix I: interview guides

### **Interview guide 1: Person with ALS (interview 1)**

#### Introduction

XX months ago you've received the diagnosis of ALS from XX (name neurologist). Can you tell me something more about how it all started, about the process of being diagnosed?

- When did you notice the first symptoms/signals?
- When did you notice that something was wrong?

When you have heard the diagnosis of XX (name neurologist). What was that for you? How did you feel? What did you think?

What were for you the biggest changes since the diagnosis? (*Changes physically, emotionally, socially*)

#### Thinking about the future

Can you tell me something more about ALS? What impact it has on you?

- Who told you this?
- What did you think/feel when you heard about this?

Do you think about your future? Is it something you think about it more than before the diagnosis or vice versa? How do you see your future now?

Option 1: Patient says (s)he thinks about the future:

- What are your expectations about the future? What do you hope for?
- What is important for you when you think about the future? What would you like to do?
- Is there something you are worried about? What are you worried about?
- Is it something you can discuss with someone? If so, who?

Option 2: Patient says (s)he does not want to think about the future:

- What makes it difficult for you to think about the future?
- Do you know if XX (name FC) thinks about the future? What would (s)he think about? Does that keep you awake? Why (not)?

#### Thinking and talking about the future

Do you think about the care you might need in the future? What do think about? What are your expectations? What are your worries? What do you hope for?

- Who gave you this information?

Option 1: Patient indicates (s)he thinks about it:

- Would that be something you would like to discuss with someone? With whom?
- In case the patient does not wish to discuss future care with FC/HCP:
  - o With whom you would like to discuss it? Why not with XX (name FC) or with HCP?
- In case the FC blocks the conversation about future/future care:
  - o How do you feel about this?
  - o What do you do when that happens?
  - o What would you like to tell him/her?
- In case there is open communication about future/future care (see questions hereinafter).
- Patient indicates future or future care is not discussed, but believe the family carer might be open for it:
  - o What do you hope to achieve with this conversation? What are your expectations?
  - o What would you like to discuss?
  - o How would that be for you to discuss your future/future care? Your worries, your ideas, your wishes, etc?
  - o When would be the best timing to have this conversation?
  - o Who should start the conversation? You, XX (name FC), HCP?
  - o Would it be important to you to discuss this first privately with FC? Why (not)?
  - o How do you think you would experience this conversation?

Option 2: Patient indicates (s)he does not wants to think about the future:

- What makes it difficult to think about the future?
- Does XX (name FC) has the same feeling?
- How would you react when XX (name FC) starts the conversation? Would you block it? Why (not)?

What are you afraid of that might happen if you talk about this?

#### Preferences about the future/future care

What is important for you when you think about your future or future care? Do you have specific wishes/ideas/preferences/expectations/hopes/etc + Ask more about the underlying values (What makes you have these wishes/ideas/XX; What is important for your when you think about your future or future care?).

*\*\*You may give examples. ATTENTION: give only examples about what you have heard during the interview. How do you feel about a wheelchair, how do you feel about travelling, etc?\**

What would be the worst care for you and what would be the best care? Why?

Patient tell his wishes/preferences/ideas during the interview:

- Have you ever discussed these wishes, XX (give some examples about what they have said) with someone? Why (not)?

Option 1: patient indicates wishes/preferences were discussed during a conversation:

- Who was present during this conversation?
- What have you talked about?
- What has triggered the conversation?
  - o Was the timing right? Why (not)?
  - o In case the timing wasn't right: When would be the right timing for you?
- How did XX (name FC) think about your preferences/wishes?
- Did you talked about it several times after that conversation? Why (not)?
- Which decisions/plans were made about future/future care?
  - o How did XX (name FC) felt about this?
  - o Do you believe that soms preferences/wishes were difficult for XX (name FC)? Why (not)? What was difficult, what not? How do you cope with that?
- Did you ever consider writing these preferences/wishes down in a living will? Why (not)?
  - o Do you believe that people close to you such as XX (name FC) knows which decisions they might need to make in case you cannot say them yourself? Why (not)?
- How did you end the conversation?
- What have you done afterwards?

Option 2: patient tells his/her wishes during interview, but indicates that (s)he did not discuss it with FC or HCP:

- Would you like to discuss your future/future care in the near or distant future? With whom?
- What is for you a barrier to have this conversation?
- What/who could help you to start this conversation? Would you like to discuss it with a HCP? If so, who?
- How would you feel, if you would want a conversation with XX (name FC) and you talk about XX (a preference that came forward during the interview), but XX (name FC) does not want it? OR How would you react if XX (name FC) would start a conversation about your future/future care?
- When would be the best timing to talk about the future or future care (for example to talk about preferred wheelchair)? Would this also be the right time to discuss XX (another preference)? Why (not)?

Option 3: patient makes it clear (s)he does not want to talk about future/future care/preferences/wishes/etc.

- What makes it difficult for you to talk about all this?
- What is the worst that may happen if you would think about it?
- Is there something you are afraid of?

Preferences about the conversation about future/future care

Option 1: In case future/future care has not been discussed yet with FC/HCP:

- When would be the right time for you?
- What makes it difficult to have this conversation?

Option 2: In case future/future care has been discussed:

- What triggered the conversation?
- Who was present? Was everyone present you would have liked to? Why (not)?
- Who supported you during this conversation?
- What made it for you the best time to discuss it? Or would you have preferred another time?

Would you discuss it again in the future? Why (not)?

End of interview

Has everything been discussed what you've had liked to discuss?

**Interview guide family carers (FC): first interview****Introduction**

XX (name patient) and you received XX months ago/ a while ago the diagnosis of ALS. Can you tell me something more about how it all started, about the process of being diagnosed?

- When did you notice the first signals/symptoms?
- When did you notice that there was something wrong?

When you have heard the diagnosis of XX (name neurologist). What was that for you? How did you feel? What did you think?

What were for you (as carer) the biggest changes since the diagnosis? (*Changes physically, emotionally, socially*)

**Thinking about the future**

What do you know about the disease/trajectory of the disease? Which impact does ALS have?

- How did you receive this information? Who told you about this?
- What did you think/feel when you've heard this?

Do you think about your future and the future of XX (name patient)? Is it something that you worry about? Are you thinking more about the future than before the diagnosis, or vice versa, do you think about it less? Or is it another way of thinking about your future? Could you tell me something more about this?

Option 1: FC says (s)he thinks about the future:

- What do you expect? What do you hope for – for you and XX (name patient)?
- What is important for you when you think about the future? What do you think is important for the future of XX (name patient)?
- What makes you worry about the future?
- With whom would you prefer to discuss the future?

Option 2: FC thinks about the future, but they do not discuss it with the patient:

- Would you like to discuss it one day with XX (name patient)?
- Do you know what (s)he thinks about? Do you know what (s)he would want or hopes or expects about the future? What do you think is important for XX (name patient)?

Option 3: FC says they do not want to think about the future:

- You say you do not want to think about the future: How come? What makes you to refuse to think about the future?
- Is it something you are afraid of and why?

How do you think XX (name patient) thinks about it? Would (s)he thinks about the future? Would (s)he worries about it?

### Thinking and talking about the future

Do you think about the care XX (name patient) might need in the future? What do you think about? What are your expectations? What do you worry about? What do you hope for?

*\*\*First asking the questions to see the perspective of the family carer AND then asking about how they think the patient thinks about these things.\*\**

- From whom did you receive information about his/her care?

Option 1: If FC thinks about future care:

- Is it something you discuss with XX (name patient)? Or with someone else? If so, who?
- If it is not possible to discuss care with patient/HCP:
  - o Would you discuss it with friends/family/other professionals/etc?
- FC says (s)he tries to discuss it, but patient does not wish to have a conversation about his/her care:
  - o How do you cope with it when you realize XX (name patient) does not want to talk about it?
  - o What do you feel/think?
  - o What would you like to say to XX (name patient)?
- FC indicates that they communicate openly about future care (go further to questions hereinafter).
- FC indicates they did not discuss future care, but thinks the patient might want to talk about it:
  - o What do you hope this conversation would trigger? What are your expectations?
  - o What would you like to say in that conversation?
  - o How would that be to discuss your worries about XX (name patient) about his/her future?
  - o When would it be important – according to you – to discuss it?
  - o How would you experience such conversation?
  - o Who should ideally start this conversation? Would you start it? Would you like that someone is there to support you? If so, who?
  - o Would you prefer to have this discussion alone with XX (name patient) or together with a HCP? Why?

Option 2: FC indicates they do not wish to think about future or future care:

- Why do you not wish to think about future care?
- Does XX (name patient) share this opinion? How do you feel about the future care?
- How would you react/What would you do if XX (name patient) or a HCP wants to discuss future care and starts this conversation? Would you block it or would you talk about it? Why?

### Preferences about the future/future care

What is important for you when you think about the future or future care of XX (name patient)?

What do you wish for? What are your preferences/ideas? Are there things you know XX (name patient) would want or would not want about care? Are there things about care you do not want?

What is – according to you important about XX's (name patient) future? What is important for you?

*\*\*Here we can give examples they have indicated during the conversation or ask how they felt about the wheelchair or walking cane etc → **ATTENTION:** listen carefully what the FC says during the interview → you cannot talk about care wishes they did not talk about. So DON'T talk about a stomach-pump if they did not talk about it): For example you might ask: how do you feel about the wheelchair? How do you think XX (name patient) feels about the wheelchair? OR I have heard you've made a lot of travels before your illness, is it something you wish to do with XX (name patient)? Do you think (s)he would enjoy this? Did you discuss it? Did you make plans? \*\**

OPTION 1: FC knows which preferences/wishes the patient has and they seem to talk about these preferences/wishes with one another:

- I hear that you have discussed it. Was there someone else present during this conversation? If so, who?
- What have you discussed?
- What did the conversation trigger? Did you believe the moment was ideal? Why?
  - o In case they did not believe the timing was ideal: When would be the best timing?
- During the conversation, have your feelings been taken into account about certain wishes/preferences/ideas/expectations/hopes/etc XX (name patient) has? Did you say how you felt/thought about it? Why and how?
  - o In case not: What makes you did not say how you felt? What might happen if you did?
- Did you make concrete plans about the future/future care?
- Have you considered to write these wishes/preferences/etc down? Why (not)?
  - o How do you feel about a living will?
- Imagine you need to make a medical decision instead of XX (name patient), would you believe that you can make this decision? In other words, do you know what XX (name patient) wants or does not want?
- How did the conversation end? What have you done afterwards?

Option 2: FC seems to know about the preferences/wishes the patient have about the future/future care, but they did not discuss it concrete:

- What makes you so sure that XX (give example about a preferences/wish) is what XX (name patient) wants? Have you ever discussed it? Did you ever talk about before diagnosis? Or is it something that you see/feel? Would you like to elaborate this more?
- Would you like to have a conversation about the preferences/wishes with XX (name patient)? Why (not)?

- What would you say or do if XX (name patient) says a wish/preference you Imagine that during this conversation XX (name patient) tells a wish/preference you cannot support?
- When would be the ideal moment for you to have this discussion?
- With whom you would like to discuss it? Only with XX (name patient) or also with HCP/kids/friends/etc?

OPTION 3: FC indicates (s)he does not know which preferences/wishes the patient has, but would like to know them:

- I hear you wish to have a conversation about the wishes/preferences XX (name patient) might have about the future/future care. Would this be something you would like to discuss alone with XX (name patient) or with a HCP or with kids/family/friends/etc?
- Would you initiate the conversation, or would you need help?
- Is there something that would make it difficult to discuss the wishes/preferences? If so, what? And what might help to overcome this barrier?
- What are the preferences you have about the future or future care of XX (name patient)?
- What do you hope to achieve in this conversation? What are your expectations?

OPTION 4: FC indicates (s)he does not know which preferences/wishes/etc the patient has, but FC does not want to know either:

- Why do you not want to know the preferences/wishes of XX (name patient)?

What is the worst possible thing that might happen if you would discuss it? Or if you would know the wishes/preferences of XX (name patient)?

#### Preferences about the conversation about future/future care

OPTION 1: FCs did not discuss wishes/preferences with patient/HCP/

- When would be the best timing to have this discussion with XX (name patient)?
- What makes it difficult to start this conversation?
- How do you think this conversation might go?
- How would you feel during such conversation?

Option 2: In case they have had this discussion:

- What triggered the conversation? How did it start?
- Who was present during this conversation? Was everyone present you and XX (name patient) would have wanted?
- Did someone help you with this conversation?
- How was the timing of this conversation? Did you feel the timing was right? Why (not)?
- How did you experience this conversation?
- Was everything discussed what you and XX (name patient) wished to discuss? Would you this conversation again in the future? Why (not)?

End of interview

Has everything been discussed what you've had liked to discuss?

**Interview patient- FC together: first interview****Introduction**

XX (name patient) and you received XX months ago/ a while ago the diagnosis of ALS. Can you tell me something more about how it all started, about the process of being diagnosed?

- When did you notice the first signals/symptoms?
- When did you notice that there was something wrong?

When you have heard the diagnosis of XX (name neurologist). What was that for you? How did you feel? What did you think?

What were for you (as patient and as carer) the biggest changes since the diagnosis? (*Changes physically, emotionally, socially*)

**Thinking about the future**

What do you know about your disease/trajectory of the disease? Which impact does ALS have?

- How did you receive this information? Who told you about this?
- What did you think/feel when you've heard this?

Do you both think about your future? Is it something that you worry about? Are you thinking more about the future than before the diagnosis, or vice versa, do you think about it less? Or is it another way of thinking about your future? Could you tell me something more about this?

Option 1: Both telling that they think about the future:

- What do you expect? What do you hope for?
- What is important for you when you think about the future?
- What makes you worry about the future?
- With whom would you prefer to discuss the future?
- Do you discuss the future together? Why (not)?

Option 2: Both think about the future, but do not discuss this:

- Would you like to discuss it one day with each other? Why (not)?
- Do you know what (s)he thinks about? Do you know what (s)he would want or hopes or expects about the future? What do you think is important?

Option 3: In case one or both does not think about the future:

- You say you do not want to think about the future: How come? What makes you to refuse to think about the future?
- Is it something you are afraid of and why?

### Thinking and talking about the future

Do you think about the care you might need in the future? What do you think about? What are your expectations? What do you worry about? What do you hope for? (patient)

Do you, as a carer think about the care XX (name patient) might need in the future? What do you think about? What are your expectations? What do you worry about? What do you hope for? (family carer)

- From whom did you receive information about the care?

Option 1: Both think about future care:

- Is it something you discuss together? Or with someone else? If so, who?
- Both indicate that they communicate openly about future care (go further to questions hereinafter).
- Both indicate they did not discuss future care, but both think about discussing it together:
  - o What do you hope this conversation would trigger? What are your expectations?
  - o What would you like to say in that conversation?
  - o How would that be to discuss your worries about XX (name patient) about his/her future and vice versa?
  - o When would it be important – according to you both – to discuss it?
  - o How would you experience such conversation?
  - o Who should ideally start this conversation? Would you start it? Would you like that someone is there to support you? If so, who?
  - o Would you prefer to have this discussion alone or together with a HCP? Why?

Option 2: Both indicate they do not wish to think about future or future care:

- Why do you not wish to think about future care?
- How do you feel about the future care?
- How would you react/What would you do if an HCP wants to discuss future care and starts this conversation? Would you block it or would you talk about it? Why?

### Preferences about the future/future care

What is important for you when you think about the future or future care?

What do you wish for? What are your preferences/ideas? Are there things you would want or would not want about care? Are there things about care you do not want? (patient)

*\*\*Here we can give examples they have indicated during the conversation or ask how they felt about the wheelchair or walking cane etc → **ATTENTION**: listen carefully what the FC says during the interview → you cannot talk about care wishes they did not talk about. So DON'T talk about a stomach-pump if they did not talk about it): For example you might ask: how do feel about the*

*wheelchair? OR I have heard you've made a lot of travels before your illness, is it something you wish to do? Did you discuss it? Did you make plans? \*\**

To family carer:

- What do you think, now you hear these preferences?
- How do you feel?
- Did you know that this was important for XX (name patient)? How did you know? Did you discuss this in the past? Why (not)?

OPTION 1: Patient expresses wishes and they have talked about these preferences/wishes with one another:

- I hear that you have discuss it. Was there someone else present during this conversation? If so, who?
- What have you discussed?
- What did the conversation trigger? Did you believe the moment was ideal? Why?
  - o In case they did not believe the timing was ideal: When would be the best timing?
- During the conversation, have your feelings been taken into account about certain wishes/preferences/ideas/expectations/hopes/etc XX (name patient) has? Did you say how you felt/thought about it? Why and how?
  - o In case not: What makes you did not say how you felt? What might happen if you did?
- Did you make concrete plans about the future/future care?
- Have you considered to write these wishes/preferences/etc down? Why (not)?
  - o How do you feel about a living will?
- Imagine you need to make a medical decision instead of XX (name patient), would you believe that you can make this decision? In other words, do you know what XX (name patient) wants or does not want?
- How did the conversation end? What have you done afterwards?

OPTION 3: FC indicates (s)he did not know which preferences/wishes the patient has, but is glad that the patient gave some wishes and preferences during the interview:

- Do you believe that you would discuss these in more depth? Why (not)? Would this be something you would like to discuss alone with XX (name patient) or with a HCP or with kids/family/friends/etc?
- Who would initiate the conversation?
- What do you hope to achieve in this conversation? What are your expectations?

OPTION 4: Both did not say any wishes or preferences, and both indicate they do not wish to discuss it:

- Why do you not want to know the preferences/wishes of XX (name patient)?
- What is the worst possible thing that might happen if you would discuss it?

Preferences about the conversation about future/future care

OPTION 1: Both did not discuss wishes/preferences with patient/HCP/

- When would be the best timing to have this discussion with XX (name patient)?
- What makes it difficult to start this conversation?
- How do you think this conversation might go?
- How would you feel during such conversation?

Option 2: In case they have had this discussion:

- What triggered the conversation? How did it start?
- Who was present during this conversation? Was everyone present you and XX (name patient) would have wanted?
- Did someone help you with this conversation?
- How was the timing of this conversation? Did you feel the timing was right? Why (not)?
- How did you experience this conversation?
- Was everything discussed what you and XX (name patient) wished to discuss? Would you this conversation again in the future? Why (not)?

End of interview

Has everything been discussed what you've had liked to discuss?

**Interview guide for patient with ALS: subsequent interviews (interview 2 and 3)**

**NOTE:** This interview guide only shows the main questions, because the subsequent interviews build upon what has been said in the previous interview.

**Introduction**

Could you tell me something more about the past 3 months, since our last conversation?

Did you think about our last conversation? Do you wish to clarify something?

What were for you the biggest changes since our last conversation? (*Changes physically, emotionally, socially*)

**Thinking about the future**

In the previous conversation, we have discussed thinking about the future. You told me XX (what they have told)

- How do you think about it now? Did it change? Why (not)?

**Thinking and talking about the future**

In the previous conversation, we have discussed talking about the future and then you have indicated you did (not) discuss the future with XX (name family carer) or with someone else

- Did you have this discussion in the past months? Why (not)?

OPTION 1: Patient did not talk about the future, and do not wish to talk about it:

- What makes it difficult to think about the future?
- Does XX (name FC) has the same feeling?
- How would you react when XX (name FC) starts the conversation? Would you block it? Why (not)?
- What are you afraid of that might happen if you talk about this?

OPTION 2: Patient thinks about the future, and wish to talk about the future, but family carer blocks the conversation:

- o How do you feel about this?
- o What do you do when that happens?
- o What would you like to tell him/her?

OPTION 3: Patient thinks about the future, and has discussed it

- What triggered the conversation?

- Who was present? Was everyone present you would have liked to? Why (not)?
- Who supported you during this conversation?
- What made it for you the best time to discuss it? Or would you have preferred another time?
- Would you discuss it again in the future? Why (not)?
  
- **NOTE:** ask how the previous interview influenced the possible conversation

#### Preferences about the future/future care

In the previous interview, we have discussed preferences about the future/future care. You said following things XX

- Did wishes/preferences/ideas change during these past months? Why (not)?
- In case wishes/preferences/ideas have changed
  - o What triggered the change in your wishes/preferences/ideas?
  - o Did you discuss these changes?
    - If so, with whom?
    - If not, why not?
- **NOTE:** ask how the previous interview influenced the possible change

In the previous interview, you told me that:

OPTION 1: you would want to discuss your preferences in the near future:

- Have you done this in the past months? Why (not)?
- In case family carers blocks the discussion:
  - o How do you feel about this?
  - o What do you do when that happens?
  - o What would you like to tell him/her?

OPTION 2: you have discussed your preferences prior to the first interview with XX (the persons they have indicated in the previous interview to whom they have discussed it)

- Have you discussed it again in the past months? Why (not)?

OPTION 3: I hear you have discussed your preferences in the past months

- What triggered the conversation?
- Who was present? Was everyone present you would have liked to? Why (not)?
- Who supported you during this conversation?
- What made it for you the best time to discuss it? Or would you have preferred another time?
- Would you discuss it again in the future? Why (not)?

OPTION 4: you have not discussed your preferences and you do not wish to discuss this

- What makes it difficult for you to talk about all this?
- What is the worst that may happen if you would think about it?
- Is there something you are afraid of?

### Preferences about the conversation about future/future care

In the previous conversation you have told me that the ideal timing for this conversation would be XX

OPTION 1: the ideal timing has arrived, but patient did not have this conversation

- Why did you not have this conversation? What stopped you?

OPTION 2: the ideal timing did not arrive, and there was no discussion in the meantime:

- Do you still have the same idea about the ideal timing to have this conversation? Why (not)?

OPTION 3: the ideal timing did not arrive, but patient did have a discussion in the past months:

- What triggered the conversation?
- Who was present? Was everyone present you would have liked to? Why (not)?
- Who supported you during this conversation?
- What made it for you the best time to discuss it? Or would you have preferred another time?
- Would you discuss it again in the future? Why (not)?

### End of interview

Has everything been discussed what you've had liked to discuss?

**Interview guide for FC: subsequent interviews (interview 2 and 3)**

**NOTE:** This interview guide only shows the main questions because the subsequent interviews build upon what has been said in the previous interview.

**Introduction**

Could you tell me something more about the past 3 months, since our last conversation?

Did you think about our last conversation? Do you wish to clarify something?

What were for you the biggest changes since our last conversation? (*Changes physically, emotionally, socially*)

**Thinking about the future**

In the previous conversation, we have discussed thinking about the future. You told me XX (what they have told)

- How do you think about it now? Did it change? Why (not)?

**Thinking and talking about the future**

In the previous conversation, we have discussed talking about the future and then you have indicated you did (not) discuss the future with XX (name patient) or with someone else

- Did you have this discussion in the past months? Why (not)?

OPTION 1: FC did not talk about the future, and do not wish to talk about it:

- What makes it difficult to think about the future?
- Does XX (name patient) has the same feeling?
- How would you react when XX (name patient) starts the conversation? Would you block it? Why (not)?
- What are you afraid of that might happen if you talk about this?

OPTION 2: FC thinks about the future, and wish to talk about the future, but patient blocks the conversation:

- o How do you feel about this?
- o What do you do when that happens?
- o What would you like to tell him/her?

OPTION 3: FC thinks about the future, and has discussed it

- What triggered the conversation?

- Who was present? Was everyone present you would have liked to? Why (not)?
- Who supported you during this conversation?
- What made it for you the best time to discuss it? Or would you have preferred another time?
- Would you discuss it again in the future? Why (not)?
- **NOTE:** ask how the previous interview influenced the possible conversation

#### Preferences about the future/future care

In the previous interview, we have discussed preferences about the future/future care. You said following things XX

- Do you believe the wishes/preferences/ideas of XX (name patient) has changed during these past months? Why (not)?
- In case wishes/preferences/ideas have changed
  - o What triggered the change in their wishes/preferences/ideas?
- **NOTE:** ask how the previous interview influenced the possible change

In the previous interview, you told me that:

OPTION 1: you would want to discuss the preferences with XX (name patient) in the near future:

- Have you done this in the past months? Why (not)?
- In case patient blocks the discussion:
  - o How do you feel about this?
  - o What do you do when that happens?
  - o What would you like to tell him/her?

OPTION 2: you have discussed with XX (name patient) the preferences prior to the first interview

- Have you discussed it again in the past months? Why (not)?

OPTION 3: I hear you have discussed the preferences with XX (name patient) in the past months

- What triggered the conversation?
- Who was present?
- Who initiated the conversation? You or XX (name patient) or someone else?
- Who supported you during this conversation?
- What made it for you the best time to discuss it? Or would you have preferred another time?
- Would you discuss it again in the future? Why (not)?

OPTION 4: you have not discussed the preferences with XX (name patient) and you do not wish to discuss this

- What makes it difficult for you to talk about all this?
- What is the worst that may happen if you would think about it?
- Is there something you are afraid of?

Preferences about the conversation about future/future care

In the previous conversation you have told me that the ideal timing for this conversation would be XX

OPTION 1: the ideal timing has arrived, but FC did not have this conversation

- Why did you not have this conversation? What stopped you?

OPTION 2: the ideal timing did not arrive, and there was no discussion in the meantime:

- Do you still have the same idea about the ideal timing to have this conversation? Why (not)?

OPTION 3: the ideal timing did not arrive, but FC did have a discussion in the past months:

- What triggered the conversation?
- Who was present?
- Who initiated the conversation? You, XX (name patient) or someone else?
- Who supported you during this conversation?
- What made it for you the best time to discuss it? Or would you have preferred another time?
- Would you discuss it again in the future? Why (not)?

End of interview

Has everything been discussed what you've had liked to discuss?