

APPENDIX E6
ALS-RELATED CLINICAL FACTORS
6.1 FAMILY HISTORY

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Follow-up questions are based on:

Q: Has any member of your immediate biological family member diagnosed with Amyotrophic lateral sclerosis, Parkinson's, or Alzheimer's disease? (Check all that apply)

ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	FOLLOW-UP QUESTIONS (SEE BELOW)
29	S6_Q03M	1	Mother	APPENDIX ITEM 6.1.1/6.1.2 SERIES
	S6_Q03F	2	Father	APPENDIX ITEM 6.1.1/6.1.3 SERIES
	S6_Q06S	3	Sister	APPENDIX ITEM 6.1.1/6.1.4 SERIES
	S6_Q06B	4	Brother	APPENDIX ITEM 6.1.1/6.1.5 SERIES
	S6_Q06C	5	Children	APPENDIX ITEM 6.1.1/6.1.6 SERIES

The following questions relate to biological family members including parents, sisters and brothers (including half siblings) and children. Please do not include adopted relatives.

APPENDIX ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION
6.1.1	S6_Q01		ONLY FOR RESPONSE 3 (SISTER) How many biological Sisters (including half-brothers) do you have, living or deceased? ENTER:
	S6_Q02		ONLY FOR RESPONSE 4 (BROTHER) How many biological Brothers (including half-brothers) do you have, living or deceased? ENTER:
	S6_Q03		ONLY FOR RESPONSE 5 (CHILDREN) How many biological Children do you have, living or deceased? ENTER:
	S6_Q01C	1 2	ONLY FOR RESPONSE 5 (CHILDREN) What is the relationship? 1 Daughter 2 Son
6.1.2	S6_Q01M	1 2 9	Is your (ITEM 29) still living? 1 Yes 2 No 9 Don't know
6.1.2.1	S6_Q02M		What is your (ITEM 29)'s current age or age at death? ENTER:
6.1.2.2			Has your (ITEM 29) ever been diagnosed by a physician with any of the following medical conditions?
6.1.2.3	S6_Q03M1	1 2	Amyotrophic lateral sclerosis: 1 Yes GO TO: APPENDIX ITEM 6.1.2.3A 2 No

		9	Don't know
6.1.2.3A			Age at diagnosis: Amyotrophic lateral sclerosis ENTER:
	S6_Q04M1		
	S6_Q04M1A	1	Don't know
6.1.2.4	S6_Q03M2		Alzheimer's disease:
		1	Yes
			GO TO: APPENDIX ITEM 6.1.2.4A
		2	No
		9	Don't know
6.1.2.4A			Age at diagnosis: Alzheimer ENTER
	S6_Q04M2		
	S6_Q04M2A	1	Don't know
6.1.2.5	S6_Q03M3		Parkinson's disease:
		1	Yes
			GO TO: APPENDIX ITEM 6.1.2.5A
		2	No
		9	Don't know
6.1.2.5A			Age at diagnosis: Parkinson ENTER
	S6_Q04M3		
	S6_Q04M3A	1	Don't know

Same questions (**APPENDIX ITEM 6.1.2 SERIES**) are asked for the chosen **family member** from Essential Questionnaire **ITEM 29**

Father	Sister	Brother	Children
APPENDIX ITEM 6.1.1/6.1.3	APPENDIX ITEM 6.1.1/6.1.4	APPENDIX ITEM 6.1.1/6.1.5	APPENDIX ITEM 6.1.1/6.1.6
S6_Q01F	S6_Q01S	S6_Q01B	S6_Q02C
S6_Q02F	S6_Q02S	S6_Q02B	S6_Q03C
S6_Q03F1	S6_Q03S1	S6_Q03B1	S6_Q04C1
S6_Q03F2	S6_Q03S2	S6_Q04B1	S6_Q05C1
S6_Q03F3	S6_Q03S3	S6_Q04B1A	S6_Q05C1A
S6_Q04F1	S6_Q04S1	S6_Q03B2	S6_Q04C2
S6_Q04F1A	S6_Q04S1A	S6_Q04B2	S6_Q05C2
S6_Q04F2	S6_Q04S2	S6_Q04B2A	S6_Q05C2A
S6_Q04F2A	S6_Q04S2A	S6_Q03B3	S6_Q04C3
S6_Q04F3	S6_Q04S3	S6_Q04B3	S6_Q05C3
S6_Q04F3A	S6_Q04S3A	S6_Q04B3A	S6_Q05C3A

**APPENDIX E6
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6.2 CLINICAL I: WEAKNESS AND SYMPTOM ONSET

Follow-up questions are based on:

Q: In what part of the body did you first notice **weakness** that was diagnosed as ALS.

ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	FOLLOW-UP QUESTIONS (SEE BELOW)
30a	S17_Q02	1	Speech and or swallowing muscles	APPENDIX 6.2.1 SERIES
		2	Arm or hand	APPENDIX 6.2.1 SERIES
		3	Neck, back or abdominal area	APPENDIX 6.2.1 SERIES
		4	Leg or foot	APPENDIX 6.2.1 SERIES
		5	Breathing muscles	APPENDIX 6.2.1 SERIES
		6	All over my body	APPENDIX 6.2.1 SERIES

Follow-up questions are based on:

Q: Before you noticed weakness that turned out to be ALS, did you experience **any of the following?** (Check all that apply)

ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	FOLLOW-UP QUESTIONS (SEE BELOW)
30b	S17_Q03A	1	Cramps	APPENDIX 6.2.1
		2	Scattered muscle twitching	APPENDIX 6.2.2
		3	Difficulty swallowing	APPENDIX 6.2.3
		4	Problem with speech	APPENDIX 6.2.4
		5	Problem with bowels or bladder control	APPENDIX 6.2.5

APPENDIX ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION
6.2.1	S17_Q01A		When did you first noticed (ITEM 30a/ITEM 30b) that was later diagnosed as ALS? Month first noticed
		1	January
		2	February
		3	March
		4	April
		5	May
		6	June
		7	July
		8	August
		9	September
		10	October
		11	November
		12	December
6.2.1.1	S17_Q01B		Year first noticed ENTER: YYYY
6.2.1.2	S17_Q01C		Don't know

Same questions (**APPENDIX ITEM 6.2.1 SERIES**) are asked for the **chosen symptoms experienced** in Essential Questionnaire **ITEM 30b**.

Cramps	Scattered muscle twitching	Difficulty swallowing	Problem with speech	Problem with bowels or bladder control
APPENDIX ITEM 6.2.1	APPENDIX ITEM 6.2.2	APPENDIX ITEM 6.2.3	APPENDIX ITEM 6.2.4	APPENDIX ITEM 6.2.5
S17_Q03A1	S17_Q03B1	S17_Q03C1	S17_Q03D1	S17_Q03E1
S17_Q03A2	S17_Q03B2	S17_Q03C2	S17_Q03D2	S17_Q03E2
S17_Q03A3	S17_Q03B3	S17_Q03C3	S17_Q03D3	S17_Q03E3

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6.3 CLINICAL II: MEDICATIONS AND ASSISTIVE DEVICE

Follow-up questions are based on:

Q: Have you ever used/had the following? (Check all that supply)

ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	FOLLOW-UP QUESTIONS (SEE BELOW)
31	S17_Q05A	1	Wheelchair/Electric scooter	APPENDIX 6.3.1 SERIES
	S17_Q05B	2	Breathing equipment (BiPap®)	APPENDIX 6.3.2 SERIES
	S17_Q05C	3	Tracheostomy	APPENDIX 6.3.3 SERIES
	S17_Q05D	4	Communication device	APPENDIX 6.3.4 SERIES
	S17_Q05E	5	Hospice program	APPENDIX 6.3.5 SERIES

APPENDIX ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION
6.3.1			When did you first use/had (ITEM 31)?
6.3.1.1	S17_Q05A1		Month first noticed
		1	January
		2	February
		3	March
		4	April
		5	May
		6	June
		7	July
		8	August
		9	September
		10	October
		11	November
		12	December
6.3.1.2	S17_Q05A2		Year first used ENTER: YYYY
6.3.1.3	S17_Q05A3		Don't know

Same questions (**APPENDIX ITEM 6.3.1 SERIES**) are asked for the **chosen items used/had** in Essential Questionnaire **ITEM 31**.

Use of BiPap or other breathing device APPENDIX ITEM 6.3.2	Tracheostomy APPENDIX ITEM 6.3.3	Alternative communication device APPENDIX ITEM 6.3.4	Hospice APPENDIX ITEM 6.3.5
S17_Q05B1	S17_Q05C1	S17_Q05D1	S17_Q05E1
S17_Q05B2	S17_Q05C2	S17_Q05D2	S17_Q05E2
S17_Q05B3	S17_Q05C3	S17_Q05D3	S17_Q05E3

Follow-up questions are based on:

Q: Are you currently taking or have you ever taken the following medication? (Check all that apply)

ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	FOLLOW-UP QUESTIONS (SEE BELOW)
33	S17_Q04	1	riluzole (Rilutek®)	APPENDIX 6.3.6
	S17_Q04A	2	edaravone (Radicava®)	APPENDIX 6.3.6

The following questions are about ALS specific medications you may have taken:

APPENDIX ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION
6.3.6		1	I have never taken (ITEM 33)
		2	I used to take (ITEM 33) but discontinued it
		3	I am currently taking (ITEM 33)
		9	Don't know

Questions below will also be asked following the medication question from **APPENDIX ITEM 6.3.6**:

APPENDIX ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION
6.3.7	S17_Q08		A multidisciplinary ALS clinic is a clinic in which specialized medical care is provided at a medical facility by a team of healthcare professionals. This team may include a neurologist, nurse, physical therapist, occupational therapist, respiratory therapist, speech-language pathologist, nutritionist or dietitian and social worker.
		1	I have never attended a multidisciplinary ALS clinic
		2	I currently attend a multidisciplinary ALS clinic
		3	I previously attended a multidisciplinary ALS clinic but do not plan to attend any further visits
		9	Don't know
6.3.8	S17_Q09		Which hand do/did you write with
		1	Right
		2	Left
		3	Can use either equally well
6.3.9	S17_Q10		Do you have advance directives established, such as a living will?
		1	Yes
		2	No
		9	Don't know
6.3.10	S17_Q11		Have you had genetic test for inherited traits that can cause ALS?
		1	Yes
		2	No
		9	Don't know

END OF SURVEY