

About you

1. Are you? Please tick one box only.

Male

Female

2. How old are you? Please write in.

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years

3. What is your ethnic group? Please tick one box only.

White

Mixed race

Asian or Asian British

Black or Black British

Other

4. In what ways are you connected to Ataxia UK? Please tick **ALL** that apply.

I am a Friend of Ataxia UK and.....

...have ataxia
myself

...live with a relative
with ataxia

...have a friend or
relative with ataxia

Other
(please write in)

5. Which type of ataxia are you or your friend/relative affected by? Please tick one box only.

Friedreich's ataxia

Confirmed diagnosis of a specific Inherited/genetic cerebellar ataxia
e.g. SCA1, SCA2, AOA1, episodic etc. (please write in which type)

Cerebellar ataxia (CA) unknown cause sometimes called sporadic/
idiopathic or cerebellar atrophy

Confirmed diagnosis of a specific non-inherited ataxia e.g. gluten ataxia or MSA

Ataxia as a symptom of another condition e.g. multiple sclerosis, stroke, alcohol or as a
result of an event e.g. accident, head injury or toxicity (please write in which condition)

Unconfirmed diagnosis of ataxia which is still being investigated

Other (please write in)

The effects of ataxia

i ONLY PEOPLE WITH ATAXIA SHOULD ANSWER QUESTIONS 8 TO 11.
IF YOU DON'T HAVE ATAXIA YOURSELF, PLEASE SKIP FORWARD TO QUESTION 12A.

8. Which of these health problems have you ever experienced due to ataxia? Please tick **ALL** that apply.

CO-ORDINATION, BALANCE MOBILITY:

- 1. Clumsiness
- 2. Using hands/dexterity
- 3. Dizziness
- 4. Balance problem/
unsteadiness
- 5. Falling
- 6. Standing
- 7. Walking
- 8. Inversion of ankles
- 9. Other mobility problem

POSTURE:

- 10. Scoliosis without spinal rod
- 11. Scoliosis with spinal rod
operation
- 12. Other posture problem

INCONTINENCE:

- 13. Bladder incontinence
- 14. Bowel incontinence

SPEECH, SWALLOWING & SALIVA:

- 15. Slurred speech/
dysarthria
- 16. Coughing/choking
- 17. Swallowing
- 18. Unable to speak
loudly enough
- 19. Drooling
- 20. Other saliva/mucus
problem

INVOLUNTARY MOVEMENTS:

- 21. Restless leg
- 22. Involuntary muscle
spasms
- 23. Involuntary tremor
- 24. Dystonia

PAIN:

- 25. Headache
- 26. Back pain
- 27. Leg or arm pain
- 28. Other pain

VISION:

- 29. Double vision
- 30. Nystagmus
- 31. Partial loss of sight
- 32. Severe visual
impairment

OTHER PROBLEMS:

- 33. Heart
- 34. Hearing
- 35. Diabetes
- 36. Cold extremities
- 37. Poor circulation
- 38. Tiredness/ fatigue/
lack of stamina
- 39. Weakness

- 40. Over Weight

OTHER:

- 41. Other (please specify)

NONE OF THESE

9. Of the problems you've ticked above at question 8, which three impact your life the most?

Please just write in the numbers below.

(e.g. if your biggest problem is "standing", then you would write in number "6" in the 1st box, etc.)

1st biggest
impact

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2nd biggest
impact

--	--

3rd biggest
impact

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**i ONLY PEOPLE WITH ATAXIA SHOULD ANSWER THE QUESTIONS ON THIS PAGE.
IF YOU DON'T HAVE ATAXIA YOURSELF, PLEASE SKIP FORWARD TO QUESTION 12A.**

10a. Have you ever experienced any of the following challenges as a result of ataxia?
Please tick **ALL** that apply below.

**(a) Difficulties you have ever experienced,
as someone with ataxia**

Please tick **ALL** that apply below.

1. Obtaining a diagnosis

2. Getting around your home

3. Getting around outside your home

4. Coping with pain

5. Looking after yourself (washing, dressing,
going to toilet, preparing meals etc.)

6. Communicating with other people/
making yourself understood

7. Feeling a lack of control over your life

8. Being accused of being drunk

9. Feeling strong emotions e.g. anger, denial,
upset, vulnerable, desperate

10. Feeling discriminated against because of ataxia

11. Feeling it's difficult to maintain your dignity

11. Of the challenges you've ticked above at question 10a, which three impact your life the most?

Please just write in the numbers below.

(e.g. if your biggest problem is "coping with pain", then you would write in number "4" in the 1st box, etc.)

1st biggest
impact

--	--

2nd biggest
impact

--	--

3rd biggest
impact

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i EVERYONE TO ANSWER QUESTION 12A ON THE NEXT PAGE

Ataxia not only affects those with the condition but also those around them, including family members and carers. We are interested to learn about the impact of ataxia on all Friends of Ataxia UK.

12a. Have you personally ever experienced any of the following challenges, as a result of having ataxia yourself, or living with or supporting someone with ataxia? Please tick **ALL** that apply below.

(a) Difficulties you have ever experienced, as a result of ataxia Please tick **ALL** that apply below.

- 1. Coping with exhaustion/fatigue
- 2. Deliberately avoiding social situations or interactions
- 3. Managing caring responsibilities (for children, spouse/partner or others)
- 4. Loneliness/isolated from family and friends
- 5. Family or relationship breakdown
- 6. Feeling uncertain how to discuss issues relating to ataxia
- 7. Not feeling very confident in dealing with ataxia
- 8. Feeling depressed
- 9. Feeling worried, anxious or fearful about the future
- 10. Lacking confidence/low self-esteem
- 11. Lack of occupation/not being able to work
- 12. Difficulty accessing education or training
- 13. Finding out about how to access social services
- 14. Finding out about benefit entitlements
- 15. Financial difficulties
- 16. Poor housing/inappropriate housing for your needs
- 17. Getting disabled adaptations to your home, that you need
- 18. Lack of suitable transport (your own or public transport)
- 19. Substance misuse (heavy drinking, drug abuse)

13. Of the challenges you've ticked above at question 12a, which four impact your life the most? Please just write in the numbers below. (e.g. if your biggest problem is "feeling depressed", then you would write in number "8" in the 1st box, etc.)

1st biggest impact **2nd** biggest impact **3rd** biggest impact **4th** biggest impact

Sources of help

14a. Have you received help or advice with any difficulties you've mentioned in this questionnaire related to ataxia from any of these sources? Please tick all you have ever used and tick any services you would like but can't access. (For any service you haven't used and don't need then please leave both the boxes blank).

14b. For each service you have USED please rate the quality of service received.

Sources of help or advice	a) Whether need or used each service. Please tick ALL that apply below.			(b) Rating of service Please tick one box on each row.		
	Would like, this service but can't access	Used now or in the past	If USED, answer b)	Excellent service, meets my needs	Good service, but need more of it	Poor service, doesn't meet my needs
Your GP	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurologist/Paediatric Neurologist	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Hospital Doctor/consultant e.g. cardiologist, orthopaedic surgeon, paediatrician (WRITE IN SPECIALISMS)	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....						
Specialist Ataxia Centre or clinic (London, Newcastle, Oxford, Sheffield)	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Geneticist/Genetic Counselling	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accident and Emergency (A&E)	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chiropodist or Podiatrist	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational Therapist	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech and Language Therapist	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
District nurse visiting you at home	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselling or psychotherapy	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paid carer/personal assistant	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Services (e.g. social worker, meals on wheels, community transport etc.)	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other source of help (WRITE IN))	<input type="checkbox"/>	<input type="checkbox"/>	>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....						

i PLEASE CHECK THAT FOR EACH SERVICE YOU HAVE USED IN COLUMN (a), YOU HAVE ALSO ANSWERED PART (b).

The role and services of Ataxia UK

16. People are Friends of Ataxia UK for different reasons. Overall, taking everything into account, please rate how important each of the following reasons are, for you personally:

Please tick one box on each row.

	Very high	High	Moderate	Low	Very low
1. To learn about ataxia causes, symptoms, research, treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Information about living with ataxia, around time of diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Information about living with ataxia, ongoing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Information about accessing State entitlements e.g. health services, benefits, housing adaptations etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Connecting with other people affected by ataxia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Helping you feel more confident to deal with your situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Supporting medical research with the aim of finding cures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Supporting Ataxia UK's work to help people affected by ataxia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Of all the reasons listed at question 16 above, which three are the most important reasons why you personally are a Friend of Ataxia UK? Please just write in the numbers below.

1st reason

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