

Our Voice, The Alliance Neurological Programme and Neurological Alliance of Scotland

Lived Experience of Neurological Conditions Survey

Informing Themes for Action and Priority in the Neurological Action Plan

We need you!

This is your opportunity to make a difference for people with neurological conditions such as Multiple Sclerosis, Epilepsy, Parkinson's Disease, Huntington's Disease, Motor Neurone Disease, Cerebral Palsy, ME, Migraine, Stroke, and Brain Injury. And if your neurological condition is not on this list, please still take part. We need to hear from a wide range of people with neurological conditions.

Now is the time for neurological conditions to take the limelight. The Scottish Government is developing an Action Plan for Neurological Conditions. The Alliance, in collaboration with the Neurological Alliance of Scotland, is gathering and leveraging the powerful voices of people like you within the neurological community.

We are seeking to shape the priorities for this upcoming action plan, and for that we need to hear from you. This survey aims to understand what your priorities are for the care and support you receive.

This is an ambitious programme where your voice can really make a difference. So thank you for telling us what you think.

If you would like us to help you complete the survey, or you require any further information or have any questions, please do not hesitate to contact Audrey Birt by e-mail at audrey.birt@alliance-scotland.org.uk

Thank you for helping us to improve the lives of people affected by neurological conditions.

1. The person completing this survey is

- A person living with a neurological condition
- Completing this survey on behalf of someone with a neurological condition



A carer of someone with a neurological condition. Questions 15 - 17 are specifically for carers. You may skip to these questions or complete the whole survey.

2. Diagnosis and Care Pathway

The need for a timely diagnosis, followed by a joined up and clear approach to care and support has been emphasised as part of this process. Thinking about when you first sought help with symptoms, do you agree or disagree with the following statements?

	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree	Does not apply to me
You were referred to a professional with experience in your condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You received the diagnosis in an acceptable timescale	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt that the professionals involved in your care are supportive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The professionals involved in your care treated you with respect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The professionals involved in your care supported you to understand your condition and symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. The most helpful information you have been given has come from:-

- My Consultant
- My GP
- The Specialist Nurse
- Voluntary Organisation
- Friends and Family
- The Internet
- Other Health Professional, such as a therapist or psychologist
- Other, please tell us more below

4.

If you answered 'Other' in the last question, please tell us about the person who has given you the most helpful information here:

5. You have a named specialist with knowledge of your condition e.g. nurse, doctor, therapist, social worker or care manager

- Yes No Don't Know

6. If you answered 'Don't Know', please tell us why:

7. You know how to contact your named specialist for support with your condition if you have a crisis or need help to manage symptoms

- Strongly agree
 Agree
 Neither agree or disagree
 Disagree
 Strongly disagree
 Does not apply to me

8. You have had support with your condition that has helped you manage your health and wellbeing better

- Strongly agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree
- Does not apply to me

9. Please tell us what has helped you manage your health and wellbeing better, here:

10. You have had information and support from the people involved in your care, about money, benefits and / or debt

- Strongly agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree
- Not Applicable to me

11. How satisfied are you with the services you have received in relation to your neurological condition, so far, from the following?

	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied	Not available to me
GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practice Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care of the Elderly Physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physiotherapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dietician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational Therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech & Language Therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuro-psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuropsychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurosurgeon	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
District Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. If you would like to tell us about other services you have received, please tell us about them here:

16. Support for Carers

Thinking about caring for someone in your situation, how much do you agree or disagree with the following statements? *Please only complete this question if you are a carer.*

	Strongly agree	Agree	Neither Agree or disagree	Disagree	Strongly disagree	Does not apply to me
As a carer I have been asked about my support needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
As a carer I have had advice, information and training to support the person I care for (e.g. giving medication, how to lift safely etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
As a carer I have had emotional support beyond family and friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
As a carer I have been given support that is right for my needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
As a carer, I have been given information and support about the benefits they are entitled to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. What is the best way to support your carer's wellbeing?

18. Communication

Thinking about the communication, between you and healthcare professionals supporting you, how much do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	Does not apply to me
I feel I am a genuine partner in my own care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Professionals involved in my care communicate clearly and use everyday language	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The professionals involved in my care gave me information about my condition and the effect of it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The professionals involved in my care continue to give me up to date information as my condition changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have received and understood information in different formats e.g. face to face, leaflets, online	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The professionals involved in my care listen to and value my concerns, views and priorities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. What does / could help communications with / between professionals involved in your care?

23. If you were to develop a training course for professionals involved in your care, what top 3 things would you want to include in this?

24. Community Neurology Services (i.e. NOT in the hospital)

Thinking of the support you need in the community or in a community setting e.g. care to support you to maintain mobility and wellbeing, how much do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither Agree or Disagree	Disagree	Strongly disagree	Does not apply to me
I am able to access community based rehabilitation from staff that understand my condition when I need it e.g. physiotherapy, occupational therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to access support in the community for respite which is suited to my needs, age and financial circumstances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to access residential facilities which are suited to someone with my condition and age	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community based care staff understand the needs of someone with my condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. What makes / could make the biggest difference to your situation accessing care and support in the community?

26. Support to self manage your condition

Thinking about how you are able to access support to help you stay well and active, how much would you agree or disagree with the following statements

	Strongly agree	Agree	Neither Agree or Disagree	Disagree	Strongly disagree	Does not apply to me
My GP, or GP practice or social worker is able to suggest services in the community like support groups and information from charities to help me live my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am aware of a local community directory of services for someone with my condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am aware of my rights and what is available to me as someone living with my condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am aware of any national groups or charities who offer information or support to people with my condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. If you are aware of any national groups or charities, how did you hear about them?

28. What in particular helps / could help you live well with your neurological condition?

29. Stigma and Social Isolation

Stigma and isolation have been raised as issues affecting people being fully involved and accepted in their communities. Thinking about how you are able to be active and involved in your community, work or family life, how much do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	Does not apply to me
I am able to/ supported to be involved, and in contact with family and friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to/supported to be involved in my community and activities I enjoy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to/ supported to take part in employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe people's attitudes have impacted on my wellbeing (positively or negatively)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. What has/would help you if you have or do feel lonely or isolated?

31. If there is anything else you want to tell us about the impact of peoples attitudes and the effect this has on your wellbeing, please tell us here:

36. What has / could make the biggest difference to you moving between services?

37. Your Views

These are all the questions relating to the themes that have already been identified.

The following questions are to understand what else, if anything, you want to highlight as having worked well for you, or as a gap, that has not already been identified to us in this survey.

Thinking about living with your condition, what other factors are important and relevant to you?

38. Thinking about living with your condition, what assumptions need to be challenged to improve living with a neurological condition?

39. Thinking about living with your condition, what development would you suggest for the future that could make the biggest difference?

40. If there anything else that you want to say, please tell us here:

41. About you

This survey is anonymous, however it would help us to understand the results, if we could collect some basic information about you.

Please tell us what neurological condition you live with. We have listed some of them here:

- Multiple Sclerosis
- Epilepsy
- Parkinson's Disease
- Huntington's Disease
- Motor Neurone Disease
- Stroke
- Brain Injury
- Headache
- Cerebral Palsy
- ME
- Prefer not to say
- Other

42. If your neurological condition is not on this list, please tell us the name of it here:

43. How long ago were you diagnosed?

- Less than 6 months ago
- Over 6 months but less than 1 year
- Over 1 year but less than 3 years ago
- Over 3 years but less than 10 years ago
- Over 10 years ago
- At Birth
- Prefer not to say

44. Please tell us:

What Year were you Born?

45. What Local Authority Area do you live in?

- | | |
|---|---|
| <input type="radio"/> Aberdeen City Council | <input type="radio"/> Aberdeenshire Council |
| <input type="radio"/> Angus Council | <input type="radio"/> Argyll & Bute Council |
| <input type="radio"/> Clackmannanshire Council | <input type="radio"/> Comhairle nan Eilean Siar / Western Isles Council |
| <input type="radio"/> Dumfries & Galloway Council | <input type="radio"/> Dundee City Council |
| <input type="radio"/> East Ayrshire Council | <input type="radio"/> East Dunbartonshire Council |
| <input type="radio"/> East Lothian Council | <input type="radio"/> East Renfrewshire Council |
| <input type="radio"/> Edinburgh City Council | <input type="radio"/> Falkirk Council |
| <input type="radio"/> Fife Council | <input type="radio"/> Glasgow City Council |
| <input type="radio"/> Highland Council | <input type="radio"/> Inverclyde Council |
| <input type="radio"/> Midlothian Council | <input type="radio"/> Moray Council |
| <input type="radio"/> North Ayrshire Council | <input type="radio"/> North Lanarkshire Council |
| <input type="radio"/> Orkney Islands Council | <input type="radio"/> Perth & Kinross Council |
| <input type="radio"/> Renfrewshire Council | <input type="radio"/> Scottish Borders Council |
| <input type="radio"/> Shetland Islands Council | <input type="radio"/> South Ayrshire Council |
| <input type="radio"/> South Lanarkshire Council | <input type="radio"/> Stirling Council |
| <input type="radio"/> West Dunbartonshire Council | <input type="radio"/> West Lothian Council |

46. What is your living situation?

- Live Alone
- Live with family / carer
- Live in Supported accomodation
- Other

47. If you chose other, please tell us about that here:

48. Thank you for taking the time to complete this questionnaire. Your help is greatly appreciated. If you are happy to be contacted further to support improving services in the future please enter your contact details below:

Name	<hr/>
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Email Address

Postal Address Line 1

Postal Address Line 2

Postal Address Line 3

If you have completed this as a paper copy, please return it by post to

Audrey Birt

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Alternatively by email to **Audrey Birt** at audrey.birt@alliance-scotland.org.uk