

National Survey of People with Long-Term Neurological Conditions

What is the survey about?

This survey is about your experiences of living with a long-term neurological condition.

Your views are very important in helping us to find out how well the health and social care provided for your condition meets your needs and how they can be improved.

Who should complete the questionnaire?

The questions should be answered by the person named on the envelope, if possible. If that person needs help to complete the questionnaire, the answers should be given from his or her point of view, not the point of view of the person who is helping.

If it is easier for you to complete the questionnaire electronically, then there is a web version at www.XXX.org.uk or you can request a Word version by e-mailing LTNC@natcen.ac.uk

Completing the questionnaire

For each question please tick clearly inside the box using a black or blue pen.

Sometimes you will find the box you ticked has an instruction to go to another question. By following these instructions carefully you will miss out questions that do not apply to you.

→ Go to **10**

Don't worry if you make a mistake; simply shade out the box and put a tick in the correct box.



Please do not write your name or address anywhere on the questionnaire.

Questions or help?

If you have any queries about the questionnaire, please call the helpline number given in the letter enclosed with this questionnaire.

**YOUR PARTICIPATION IN THIS SURVEY IS VOLUNTARY.
IF YOU CHOOSE TO TAKE PART, YOUR ANSWERS WILL BE TREATED IN
CONFIDENCE**

DIAGNOSIS

The following questions are about when you first found out that you had a neurological condition.

1

When did you first find out that you had a neurological condition?

1015-1016

Tick one box

Less than 1 year ago 1

1 to 2 years ago 2

3 to 4 years ago 3

5 to 10 years ago 4

More than 10 years ago 5

I don't remember 6

2

Were you told about your condition in a considerate way?

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

I don't remember 4

Still thinking about when you first found out that you had a neurological condition...

3

Were you given enough information about how your condition would *affect your everyday life*?

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No, but I would have liked some 3

I did not need any information 4

I don't remember 5

Still thinking about when you first found out that you had a neurological condition...

4 Were you given enough information about how your condition might *change over time*?

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No, but I would have liked some 3

I did not need any information 4

I don't remember 5

5 Were you given enough information about options for your *care and treatment*?

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No, but I would have liked some 3

I did not need any information 4

I don't remember 5

6 Were you given enough information about how to *manage your condition*?

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No, but I would have liked some 3

I did not need any information 4

I don't remember 5

7 How much *written information* were you given about your condition?

1015-1016

Tick one box

Not enough 1

About the right amount 2

Too much 3

I don't remember 4

8

Were you given an opportunity to *talk through* the implications of your condition?

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

I don't remember 4

YOUR CARE PLAN

These questions are about the care and support you have received since your diagnosis

9

Are you aware of a *care plan* for your neurological condition? (Your care plan shows what health and/or social care services you need, and who will provide them for you)

Tick one box

Yes 1 → Go to **10**

No 2 → Go to **12**

10

Have you been given or offered a *written or printed copy* of your care plan?

Tick one box

Yes 1

No 2

Don't know 3

11

As far as you know, is your care plan kept up to date?

Tick one box

Yes 1

No 2

Don't know 3

PLANNING YOUR CARE

12

Do you feel as involved as you would like to be in making decisions about your care?

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

Don't know 4

13

Do you have a *named health or social care professional* that you can contact for advice and information about your neurological condition?

1015-1016

Tick one box

Yes, one named contact 1

Yes, more than one named contact 2

No 3

Don't know 4

14

Do you feel that all the health and/or social care professionals caring for you *work well together* in planning your neurological care?

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

Don't know 4

HEALTH CARE PROFESSIONALS

The following questions ask about some of the health care professionals who may be involved in providing care for your neurological condition.

15

In the last 12 months, have you seen a *neurologist* at a hospital or clinic about your neurological condition?

1015-1016

Tick one box

Yes 1 → Go to **16**

No 2 → Go to **19**

Don't know / Not sure 3 → Go to **19**

Thinking of the last time you saw a neurologist about your neurological condition...

16

Did the neurologist *listen carefully* to what you had to say?

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

Don't know 4

17 Were you given *enough time to discuss your condition or treatment with the neurologist?*

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

I did not need to discuss anything 4

18 If you had questions, did you get *answers that you could understand?*

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

I did not need to ask questions 4

I did not have an opportunity to ask questions 5

19 Have you seen a **GP** about your neurological condition in the *last 12 months?*

Tick one box

Yes 1 → Go to **20**

No 2 → Go to **23**

Thinking of the last time you saw a GP about your neurological condition...

20 Did the GP *listen carefully to what you had to say?*

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

Don't know 4

21

Were you given *enough time to discuss your condition or treatment with the GP?*

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

I did not need to discuss anything 4

22

If you had questions, did you get *answers that you could understand?*

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

I did not need to ask questions 4

I did not have an opportunity to ask questions 5

SOCIAL CARE AND OTHER SUPPORT

The following questions ask about any support you may have received to help you cope with your condition and live more independently.

23

In the last 12 months, have you had any help from health and/or social care staff with your **personal care at home** (such as dressing, washing, or eating)?

1015-1016

Tick one box

Yes 1 → Go to **24**

No, but I would have liked some 2 → Go to **25**

No, I did not need it 3 → Go to **25**

24

How well did the help you received with **personal care at home meet your needs?**

1015-1016

Tick one box

Very well 1

Fairly well 2

Not very well 3

Don't remember 4

25

In the last 12 months, have you received any *emotional and/or psychological support* from health or social care professionals, to help you cope with your neurological condition?

1015-1016

Tick *one* box

Yes ¹ → Go to **26**

No, but I would have liked some ² → Go to **27**

No, I did not need it ³ → Go to **27**

26

Did you find this support helpful?

1015-1016

Tick *one* box

Yes, definitely ¹

Yes, to some extent ²

No ³

27

Since your diagnosis, have you received any advice from health or social care services on getting *welfare benefits* (eg Disability Living Allowance)?

1015-1016

Tick *one* box

Yes ¹

Some, but not enough ²

No, but I would have liked advice ³

No, I did not need advice ⁴

REHABILITATION

The questions in this section are about rehabilitation. If this is not relevant for your neurological condition, please indicate this at Q28 and then go to question Q33.

28

Have you received any *rehabilitation support* for your condition?

1015-1016

Tick *one* box

Rehabilitation is not relevant for my condition ¹ → Go to **33**

Yes ² → Go to **29**

No, but I would have liked some ³ → Go to **33**

No, I don't need any ⁴ → Go to **33**

Don't know ⁵ → Go to **33**

29

Do you feel you have received *enough* rehabilitation support?

1015-1016

Tick one box

Yes 1

No, a little less than I would have liked 2

No, a lot less than I would have liked 3

Don't know or too early to say 4

30

Have you been offered rehabilitation support at a *location* that is convenient for you?

1015-1016

Tick one box

Yes, always 1

Yes, some of the time 2

No 3

31

Have you been offered rehabilitation support *at times* that are convenient for you?

1015-1016

Tick one box

Yes, always 1

Yes, some of the time 2

No 3

32

Overall, has the rehabilitation support you have received so far made it easier for you to live more independently?

1015-1016

Tick one box

Yes, definitely 1

Yes, to some extent 2

No 3

Don't know or too early to say 4

EQUIPMENT AND ADAPTATIONS

The following questions ask about:

- Any adaptations – these are changes that have been made to your home to help you live with your condition (eg bathroom adaptations, stair lift, hand rails).
- Other aids or equipment (eg wheelchair, walking stick, computer software).

33 Have you ever had *an assessment* for any adaptations, aids or equipment that you might need in relation to your neurological condition?

1015-1016

Tick *one* box

Yes, I had an assessment 1

No, but I would have liked an assessment 2

No, I did not need an assessment 3

Don't know 4

34 Since you were diagnosed with your neurological condition, have you moved to more *suitable* accommodation?

1015-1016

Tick *one* box

Yes 1

No 2

35 Have any adaptations been made to your current accommodation to help you live with your condition?

1015-1016

Tick *one* box

Yes 1 → Go to **36**

No, but I would have liked some 2 → Go to **37**

No, I did not need any 3 → Go to **39**

36 Have the adaptations made to your accommodation made it easier for you to live more independently?

1015-1016

Tick *one* box

Yes, definitely 1

Yes, to some extent 2

No 3

37 Have you tried to arrange any adaptations through health or social services?

Tick one box

Yes ¹ → Go to **38**

No ² → Go to **39**

38 If so, have either of the following been a problem for you?

Tick one box on each line

Yes No

Finding out how to arrange adaptations through health or social services ¹ ²

66

The length of time it takes to arrange adaptations ¹ ²

67

39 Since you were diagnosed with your condition, have you *bought or been given* any aids or equipment to help you live with your condition?

Tick one box

Yes, all I need ¹ → Go to **40**

Yes, some of what I need ² → Go to **40**

No, but I would like some ³ → Go to **41**

No, I don't need any ⁴ → Go to **45**

40 Have the aids or equipment made it easier for you to live more independently?

Tick one box

Yes, definitely ¹

Yes, to some extent ²

No ³

41 Have you tried to get any aids or equipment through health or social services?

Tick one box

Yes ¹ → Go to **42**

No ² → Go to **43**

42

If so, have any of the following been a problem for you?

Tick one box on each line

Yes No

Finding out how to get hold of suitable aids or equipment ¹ ² 66

The length of time it takes to get aids or equipment ¹ ² 67

The standard of aids or equipment available ¹ ² 68

43

Have you *bought or tried to buy* any aids or equipment independently?

1015-1016

Tick one box

Yes ¹ → Go to **44**

No ² → Go to **45**

44

If so, have any of the following been a problem for you?

Tick one box on each line

Yes No

Finding out how to get hold of suitable equipment ¹ ² 66

Knowing what equipment I need ¹ ² 67

The price of equipment ¹ ² 68

ABOUT YOU

These questions ask for some information about you. This will be used to look at patterns of experience of health and social services of different groups of people.

If you are filling in this questionnaire on behalf of the person it was sent to, please do fill in this section referring to the person this survey was sent to, rather than about yourself.

45

What is the common name of the neurological condition that you have?

1015-1016

(Please write in)

46

Are you male or female?

1015-1016

Male 1

Female 2

47

What was your year of birth?

1015-1016

(Please write in)

| | | | |
|---|---|--|--|
| 1 | 9 | | |
|---|---|--|--|

48

What is your employment status?

1015-1016

Tick all that apply

In paid employment (full-time or part-time) 1

In full-time education 2

Working on a casual or voluntary basis 3

Not working, but looking for work 4

Permanently unable to work because of long-term sickness or disability 5

Retired from paid work 6

Looking after the home or family 7

Doing something else 8

49

Do you live with any of the following people?

1015-1016

Tick all that apply

With spouse or partner 1

With parent(s) 2

With son(s) or daughter(s) 3

With other relative(s) or friends 4

I live in a group living setting or assisted living 5

I live in a residential care home 6

None of the above, I live alone 7

Other (*please specify*) 8

50

Do you receive any care or support for your neurological condition from any of the following people?

1015-1016

Tick all that apply

Spouse or partner 1

Parent(s) 2

Son(s) or daughter(s) 3

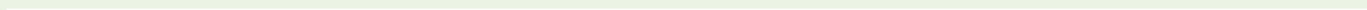
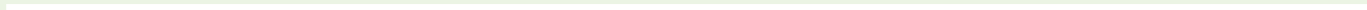
Other relative(s) 4

Friends or neighbours 5

Paid care workers 6

Other 7

OR, I don't need any care or support for my neurological condition 8



51

To which of the following ethnic groups would you say you belong?

Tick one box

White

British 1

Irish 2

Any other white background (*please write in*) 3

4

Mixed

White and black Caribbean 5

White and black African 6

White and Asian 7

Any other mixed background (*please write in*) 8

Asian or Asian British

Indian 9

Pakistani 10

Bangladeshi 11

Any other Asian background (*please write in*) 12

Black or black British

Caribbean 13

African 14

Any other black background (*please write in*) 15

Chinese or other ethnic group

Chinese 16

Any other ethnic group (*please write in*) 17

*Tick all that apply*The person named on the envelope 1A friend or relative of the person named on the envelope 2A paid carer 3Someone else 4**Is there anything particularly good about your care?****Is there anything that could be improved?****Anything else you would like to tell us?****Thank you for completing the questionnaire.****Please make sure that you have answered all questions that apply to you.****Please post this questionnaire back to us in the FREEPOST envelope provided.**