
















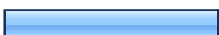
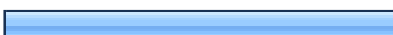
1. How old are you?

		Response Percent	Response Count
Under 18		0.0%	0
18 - 30		0.0%	0
31 - 50		30.6%	11
51 - 65		36.1%	13
Over 65		33.3%	12
answered question			36
skipped question			8


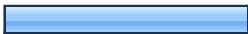

2. What neurological condition(s) do you have?

		Response Percent	Response Count
Motor Neurone Disease		10.0%	3
Multiple Sclerosis		36.7%	11
Parkinsons		20.0%	6
Epilepsy		3.3%	1
Progressive Supranuclear Palsy		0.0%	0
Migraine		3.3%	1
Brain tumour		3.3%	1
Alzheimers / dementia		3.3%	1
Brain injury		6.7%	2
ME		10.0%	3
Myasthenia Gravis		3.3%	1
Stroke		6.7%	2
	Other (please specify)		7
answered question			30
skipped question			14

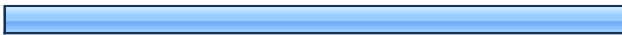
3. How long have you had this condition? (when symptoms started, or you were given the diagnosis, whichever was the earliest).

		Response Percent	Response Count
under a year		2.9%	1
1 - 5 years		34.3%	12
over 5 years		62.9%	22
answered question			35
skipped question			9

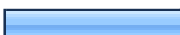
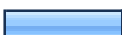
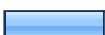


4. What are the first two letters of your postcode?

		Response Percent	Response Count
BA		36.1%	13
SN		38.9%	14
SP		25.0%	9
Other (please specify)			0
answered question			36
skipped question			8




5. What is your ethnic origin?

		Response Percent	Response Count
White (British, Irish or other origin)		100.0%	35
Asian (British, or of Indian, Pakistani, Bangladeshi, Chinese or other origin)		0.0%	0
Black (British or of African, Caribbean or other origin)		0.0%	0
Mixed origin.		0.0%	0
answered question			35
skipped question			9

6. From the date of your first visit to your doctor, how long did it take for you to be given a definite diagnosis?

		Response Percent	Response Count
under 3 months		28.1%	9
3 - 6 months		18.8%	6
6 - 12 months		15.6%	5
over a year		31.3%	10
I have never had a definite diagnosis		6.3%	2
answered question			32
skipped question			12

7. When you first reported your symptoms to a doctor, did either you or the doctor suspect that they resulted from a long-term neurological condition?

		Response Percent	Response Count
yes		22.6%	7
no		58.1%	18
don't know / don't remember		19.4%	6
Other (please specify)			3
answered question			31
skipped question			13

8. Have you been referred to a consultant neurologist, or any other consultant specialising in your condition, at any point?

		Response Percent	Response Count
yes		90.9%	30
no		9.1%	3
don't know / don't remember		0.0%	0
answered question			33
skipped question			11

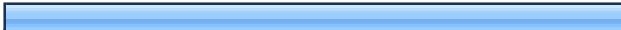
9. Were you offered counselling / emotional support after your diagnosis?

		Response Percent	Response Count
yes		21.2%	7
no		72.7%	24
don't know / don't remember		6.1%	2
answered question			33
skipped question			11




10. Did you receive information concerning what treatment might be available for you?

		Response Percent	Response Count
yes		51.2%	22
no		32.6%	14
don't know / don't remember		16.3%	7
answered question			43
skipped question			1




















11. Why was this?

		Response Percent	Response Count
treatment for my condition was not available		100.0%	8
treatment for my condition was not required		0.0%	0
I refused treatment		0.0%	0
answered question			8
skipped question			36

12. Was treatment from specialist neurological services, or other specialist services, available as soon as you needed it after your diagnosis?

		Response Percent	Response Count
yes		53.3%	16
no		33.3%	10
don't know / don't remember		13.3%	4
answered question			30
skipped question			14

13. Which professionals / organisations have you received services from in the last 12 months?

		Response Percent	Response Count
physiotherapist		48.5%	16
occupational therapist		42.4%	14
GP		84.8%	28
community nurse		15.2%	5
speech and language therapist		15.2%	5
dietician		6.1%	2
continence nurse		9.1%	3
social services		30.3%	10
care manager		6.1%	2
voluntary organisation/charity		48.5%	16
community matron		0.0%	0
specialist nurse/co-ordinator		45.5%	15
neurologist / consultant / elderly care consultant		54.5%	18
neurosurgeon		3.0%	1
hospice		6.1%	2
psychologist		9.1%	3
intensive care staff		0.0%	0
tissue viability nurse		6.1%	2
orthotist		6.1%	2
mental health worker		3.0%	1
none		3.0%	1

Other (please specify) 2

answered question 33

skipped question

11

14. Are there any services that you would like to have but you're not currently getting?

		Response Percent	Response Count
yes		34.1%	14
no		34.1%	14
don't know		31.7%	13
answered question			41
skipped question			3

15. Please say which ones

	Response Count
	12
answered question	12
skipped question	32



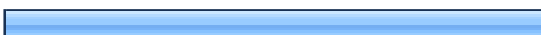






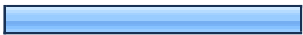

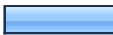


16. Overall, do you feel that the way services are provided are based around your needs rather than the needs of the professional or the services?

		Response Percent	Response Count
yes		15.2%	5
mostly		21.2%	7
partly		36.4%	12
no		24.2%	8
don't know		3.0%	1
answered question			33
skipped question			11

17. Can you refer yourself into any health and social care services?

		Response Percent	Response Count
yes		53.1%	17
no		6.3%	2
don't know		40.6%	13
answered question			32
skipped question			12

18. Which ones are you able to refer yourself to?

		Response Percent	Response Count
physiotherapist		17.4%	4
occupational therapist		26.1%	6
GP		87.0%	20
community nurse		13.0%	3
speech and language therapist		4.3%	1
dietician		4.3%	1
continence nurse		13.0%	3
social services		34.8%	8
care manager		4.3%	1
voluntary organisation/charity		47.8%	11
community matron		0.0%	0
specialist nurse/co-ordinator		34.8%	8
neurologist		17.4%	4
neurosurgeon		0.0%	0
hospice		0.0%	0
psychologist		8.7%	2
intensive care staff		0.0%	0
tissue viability nurse		0.0%	0
orthotist		0.0%	0
mental health worker		8.7%	2
none		0.0%	0

Other (please specify) 5

answered question 23

skipped question 21









19. Can you easily get health and social care services if your needs change?

		Response Percent	Response Count
yes		25.8%	8
no		12.9%	4
don't know		61.3%	19
answered question			31
skipped question			13

20. Do you have a named person / key worker who helps you get the health and social care services you need?

		Response Percent	Response Count
yes		29.7%	11
no		59.5%	22
don't know		10.8%	4
answered question			37
skipped question			7

21. Who is this?

		Response Percent	Response Count
physiotherapist		11.1%	1
occupational therapist		33.3%	3
GP		66.7%	6
community Nurse		11.1%	1
speech and language therapist		0.0%	0
dietician		0.0%	0
continence nurse		0.0%	0
social services		11.1%	1
care manager		0.0%	0
voluntary organisation/charity		11.1%	1
community matron		0.0%	0
specialist nurse/co-ordinator		66.7%	6
neurologist		11.1%	1
neurosurgeon		0.0%	0
hospice		0.0%	0
psychologist		0.0%	0
intensive care staff		0.0%	0
tissue viability nurse		0.0%	0
orthotist		0.0%	0
mental health worker		0.0%	0
none		0.0%	0

Other (please specify) 1

answered question 9

skipped question 35

22. Do you use both health and social services?

		Response Percent	Response Count
yes		45.9%	17
no		45.9%	17
don't know		8.1%	3
answered question			37
skipped question			7

23. Have you been asked whether it would be OK for social services and health professionals to share information about you with each other?

		Response Percent	Response Count
yes		25.0%	4
no		43.8%	7
don't know / don't remember		31.3%	5
answered question			16
skipped question			28

24. If you are receiving services from both health and social care, do you feel that the professionals work together to offer you a services that meet your needs?

		Response Percent	Response Count
yes		6.3%	1
mostly		12.5%	2
sometimes		18.8%	3
no		37.5%	6
don't know		25.0%	4
answered question			16
skipped question			28



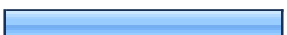

25. Have you ever paid privately to see any professional about your neurological condition?

		Response Percent	Response Count
yes		32.4%	12
no		67.6%	25




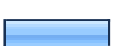
If yes, please say who e,g Physiotherapist, Consultant Neurologist: 12

answered question			37
skipped question			7

26. Please say why you paid privately

		Response Percent	Response Count
for a second opinion		11.1%	1
didn't like the professional I was referred to		0.0%	0
had to wait too long		55.6%	5
to speed up my diagnosis		44.4%	4
had health insurance		11.1%	1
	Other reason - please state:		4
answered question			9
skipped question			35

27. Have you been offered a direct payment to enable you to buy and manage your own social care?

		Response Percent	Response Count
yes		41.7%	5
no		33.3%	4
don't know / don't remember		8.3%	1
not applicable		16.7%	2
answered question			12
skipped question			32

28. Have you accepted?

		Response Percent	Response Count
yes		55.6%	5
no		44.4%	4
answered question			9
skipped question			35

29. Have you ever been on a course, or a programme designed to help you manage your own condition better (eg the Expert Patient Programme)?

		Response Percent	Response Count
yes		24.2%	8
no		75.8%	25
answered question			33
skipped question			11

30. Do you have a written care plan? (i.e. a document that sets out your current and anticipated needs, and how they will be met).

		Response Percent	Response Count
yes		16.2%	6
no		67.6%	25
don't know		16.2%	6
answered question			37
skipped question			7

31. Were you fully involved in writing the plan?

		Response Percent	Response Count
yes		100.0%	5
no		0.0%	0
answered question			5
skipped question			39

32. Is your care plan regularly reviewed?

		Response Percent	Response Count
yes		60.0%	3
no		20.0%	1
only if there is a change in my condition		20.0%	1
answered question			5
skipped question			39

33. At diagnosis were you offered / given information on your condition by health and social care professionals?

		Response Percent	Response Count
yes		37.5%	12
no		40.6%	13
yes, but didn't want any information at the time.		12.5%	4
don't know / don't remember		9.4%	3
answered question			32
skipped question			12

34. At diagnosis were you offered / given information on the health and / or social care services that could help you?

		Response Percent	Response Count
yes		18.8%	6
no		56.3%	18
yes, but didn't want any information at the time.		9.4%	3
don't know / don't remember		15.6%	5
answered question			32
skipped question			12

35. At diagnosis were you given information about other organisations (e.g voluntary organisations/charities, housing, employment services) that could provide you with information, advice and support?

		Response Percent	Response Count
yes		34.4%	11
no		50.0%	16
yes, but didn't want any information at the time.		6.3%	2
don't know / don't remember		9.4%	3
answered question			32
skipped question			12


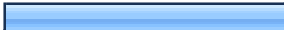




36. Are you regularly asked by health or social care staff whether there is any information that you would like?

		Response Percent	Response Count
yes		21.9%	7
sometimes		18.8%	6
no		53.1%	17
not currently applicable		6.3%	2
answered question			32
skipped question			12






37. Do you think you get all the information you need to make the most of your local services?

		Response Percent	Response Count
yes		18.8%	6
no		50.0%	16
I do not want any information		0.0%	0
don't know		31.3%	10
answered question			32
skipped question			12

**38. Where / how do you get your information now about what services are available?
Please select all that apply**

		Response Percent	Response Count
I don't currently want information		6.9%	2
GP		44.8%	13
consultant neurologist or other doctors		31.0%	9
other health and social care staff that you deal with		24.1%	7
internet search		44.8%	13
voluntary organisations		58.6%	17
	Other (please specify)		2
answered question			29
skipped question			15

39. Do you think that the health and social care professionals with whom you are in contact recognise "hidden disabilities" that you may have e.g cognitive impairments, communication difficulties?

		Response Percent	Response Count
yes		25.8%	8
mostly		19.4%	6
not very often		22.6%	7
no		22.6%	7
not applicable		9.7%	3
answered question			31
skipped question			13

40. Do you think that the health and social care professionals with whom you are in contact recognise emotional and psychological problems e.g. anxiety, depression?

		Response Percent	Response Count
yes		19.4%	6
mostly		35.5%	11
not very often		12.9%	4
no		19.4%	6
not applicable		12.9%	4
answered question			31
skipped question			13

41. Do they listen to, and take fully into account, your views and wishes?

		Response Percent	Response Count
yes		41.9%	13
mostly		38.7%	12
not very often		3.2%	1
no		9.7%	3
not applicable		6.5%	2
answered question			31
skipped question			13

42. Have you ever been admitted to hospital as an emergency as a direct result of your neurological condition?

		Response Percent	Response Count
yes		35.1%	13
no		64.9%	24
answered question			37
skipped question			7

43. What type of care did you receive?

		Response Percent	Response Count
immediate and appropriate treatment on a neurological ward		16.7%	2
immediate and appropriate treatment on a general ward		58.3%	7
inappropriate and unsatisfactory treatment on a general ward		16.7%	2
inappropriate or unsatisfactory treatment on a neurological ward		8.3%	1
answered question			12
skipped question			32

44. Have you ever experienced a sudden change in your life because of the sudden onset of a neurological condition (e.g. traumatic brain or spinal cord injury)?

		Response Percent	Response Count
yes		31.4%	11
no		68.6%	24
answered question			35
skipped question			9

45. Have you been offered a referral to a psychologist to help you adjust to your changed circumstances since diagnosis?

		Response Percent	Response Count
yes, and I accepted		3.7%	1
yes, but declined		3.7%	1
no		74.1%	20
no, not applicable		11.1%	3
can't remember		7.4%	2
answered question			27
skipped question			17

46. Have your family been offered a referral to a psychologist to help them adjust to your changed circumstances since diagnosis?

		Response Percent	Response Count
yes, and it was accepted		3.7%	1
yes, but declined		0.0%	0
no		77.8%	21
no, not applicable		11.1%	3
can't remember		7.4%	2
answered question			27
skipped question			17

47. In the last 3 years, have you been admitted to hospital for a problem that was nothing to do with your neurological condition?

		Response Percent	Response Count
yes		28.6%	10
no		71.4%	25
	If yes (please specify)		8
answered question			35
skipped question			9

48. Did you feel that the staff understood the needs of people with your condition?

		Response Percent	Response Count
yes		22.2%	2
no		33.3%	3
to some extent		44.4%	4
don't know / don't remember		0.0%	0
answered question			9
skipped question			35

49. Did the staff listen to you and / or your carers about any special needs/issues you had because of your neurological condition?

		Response Percent	Response Count
yes		33.3%	3
no		33.3%	3
to some extent		33.3%	3
don't know / don't remember		0.0%	0
answered question			9
skipped question			35

50. Did the staff seek help or advice from specialist neurology staff?

		Response Percent	Response Count
yes		33.3%	3
no		33.3%	3
don't know / don't remember		33.3%	3
answered question			9
skipped question			35

51. Have you given up your job because of your neurological condition?

		Response Percent	Response Count
yes - retirement on medical grounds		45.7%	16
yes - voluntarily		11.4%	4
no		20.0%	7
no - but I have changed from full-time to part-time employment		2.9%	1
not applicable - was not in paid employment / was retired		20.0%	7
answered question			35
skipped question			9

52. Would you like to return to paid employment of some type of work now, or would you have liked to have returned to paid employment at some point since giving up work?

		Response Percent	Response Count
yes		61.5%	16
no		38.5%	10
answered question			26
skipped question			18

53. Have you been / were you offered any rehabilitation or other support or advice to help you return to work (e.g access to work)?

		Response Percent	Response Count
yes		21.4%	3
no		78.6%	11
answered question			14
skipped question			30

54. Within the last 3 years, have you had any services (including information and advice) to help you to be as independent as possible at home and in the community?

		Response Percent	Response Count
yes		55.9%	19
no		44.1%	15
answered question			34
skipped question			10

55. Has this included any equipment e.g wheelchair, grab rails, emergency call button?

		Response Percent	Response Count
yes		78.9%	15
no		21.1%	4
can't remember		0.0%	0
answered question			19
skipped question			25

56. Did you feel you had to wait an unreasonable length of time for any of these things?

		Response Percent	Response Count
yes		13.3%	2
no		86.7%	13

If yes, please say, if you can, which ones and approximately how long you waited? 4

answered question			15
skipped question			29

57. Have you had physiotherapy to maintain or improve your functioning?

		Response Percent	Response Count
yes		54.5%	18
no		30.3%	10
not needed any		15.2%	5
answered question			33
skipped question			11

58. Was it limited to a specific number of sessions?

		Response Percent	Response Count
yes		66.7%	12
no		27.8%	5
don't know		5.6%	1
answered question			18
skipped question			26

59. Do you have paid carers to help you in the home with your personal care (eg. washing, getting dressed, getting to bed) or household activities (eg. shopping, laundry, housework)?

		Response Percent	Response Count
yes		30.3%	10
no		48.5%	16
no, but I feel I need some help		21.2%	7
answered question			33
skipped question			11

60. Is this arranged by social services?

		Response Percent	Response Count
yes		55.6%	5
no		44.4%	4
answered question			9
skipped question			35

61. Are the services provided in a way that meets your wishes about how you want to live (e.g. you get to bed at a time that suits you: the carers treat you with dignity and respect)?

		Response Percent	Response Count
yes		50.0%	4
no		12.5%	1
mostly		25.0%	2
to some extent		12.5%	1
What changes, if any, would you want to make?			3
answered question			8
skipped question			36

62. Have health and social care professionals arranged for any adaptations to your home to help you to remain living there e.g. ramps, downstairs bedroom?

		Response Percent	Response Count
yes		48.5%	16
no		51.5%	17
answered question			33
skipped question			11

63. Did you feel that you had to wait an unreasonable length of time for any of the adaptations?

		Response Percent	Response Count
yes		7.1%	1
no		92.9%	13

If yes, please say which ones: 2

answered question	14
skipped question	30

64. Whether or not you have had adaptations to your home, do you think that you now need to move to different accommodation in order to remain independent?

		Response Percent	Response Count
yes		9.1%	3
no		90.9%	30

answered question	33
skipped question	11

65. Are you on a waiting list to move?

		Response Percent	Response Count
yes		33.3%	1
no		66.7%	2

answered question	3
skipped question	41

66. How long have you been waiting?

		Response Percent	Response Count
less than 3 months		0.0%	0
3 - 6 months		0.0%	0
7 - 12 months		100.0%	1
1 - 2 years		0.0%	0
more than 2 years		0.0%	0
answered question			1
skipped question			43

67. Do you have a carer, i.e. a partner, family member or friend who helps you on a day-day basis?

		Response Percent	Response Count
no		17.9%	5
yes - spouse/partner		67.9%	19
yes - relative		10.7%	3
yes - friend		3.6%	1
other (please specify)			6
answered question			28
skipped question			16






68. Has your carer been offered any training to provide care and support for you?

		Response Percent	Response Count
yes		3.6%	1
no		64.3%	18
yes , but they didn't want it		3.6%	1
don't know / don't remember		7.1%	2
not applicable		21.4%	6
answered question			28
skipped question			16

69. Has your main carer been offered an assessment of their needs?

		Response Percent	Response Count
yes		13.8%	4
no		58.6%	17
yes , but they didn't want it		3.4%	1
don't know / don't remember		0.0%	0
not applicable		24.1%	7
answered question			29
skipped question			15

70. Do the professionals you come into contact with listen to your family and/or carer/s?

		Response Percent	Response Count
always		34.5%	10
mostly		20.7%	6
sometimes		13.8%	4
never		3.4%	1
not applicable		27.6%	8
answered question			29
skipped question			15





71. What do you value / like most about the services you currently use (or have used in the recent past)?

	Response Count
	22
answered question	22
skipped question	22

72. What do you least like about the services you currently use (or have used in the recent past)?

	Response Count
	20
answered question	20
skipped question	24

73. Overall, in the last 3 years do you think your local services have: (or however long you've been using services if less than 3 years)




		Response Percent	Response Count
improved		19.2%	5
got worse		30.8%	8
stayed about the same		30.8%	8
not sure whether or not they've changed		19.2%	5

Can you give specific examples of any changes for the better and / or for the worse 8

answered question 26

skipped question 18

74. Are there any services that you think should be available but which aren't currently in place?

		Response Percent	Response Count
yes		44.0%	11
no		20.0%	5
don't know		36.0%	9

If yes could you give examples? 13

answered question 25

skipped question 19

75. Do you think that the way some services are provided should change?

		Response Percent	Response Count
yes		37.5%	9
no		16.7%	4
don't know		45.8%	11

If yes could you give examples? 12

answered question	24
skipped question	20

76. What would make the biggest improvement for you, living with a long-term neurological condition?

	Response Count
	21
answered question	21
skipped question	23

77. If you would like, Please write any further comments or questions in the box below. If you would like to discuss any of the issues in this questionnaire further, please leave your name and contact details

	Response Count
	8
answered question	8
skipped question	36