
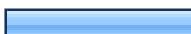

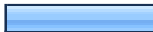


1. How old are you?

		Response Percent	Response Count
Under 18		2.0%	1
18 - 30		0.0%	0
31 - 50		30.0%	15
51 - 65		44.0%	22
Over 65		24.0%	12
answered question			50
skipped question			0




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

		Response Percent	Response Count
Motor Neurone Disease		4.4%	2
Multiple Sclerosis		40.0%	18
Parkinsons		0.0%	0
Epilepsy		4.4%	2
Progressive Supranuclear Palsy		2.2%	1
Migraine		8.9%	4
Brain tumour		0.0%	0
Alzheimers / dementia		2.2%	1
Brain injury		2.2%	1
ME		24.4%	11
Myasthenia Gravis		0.0%	0
Stroke		17.8%	8
	Other (please specify)		8
answered question			45
skipped question			5


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		4.0%	2
1 - 5 years		26.0%	13
over 5 years		70.0%	35
answered question			50
skipped question			0






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

		Response Percent	Response Count
BA		2.0%	1
SN		95.9%	47
SP		2.0%	1
Other (please specify)			1
answered question			49
skipped question			1




5. What is your ethnic origin?

		Response Percent	Response Count
White (British, Irish or other origin)		100.0%	49
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			49
skipped question			1

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		14.6%	7
3 - 6 months		22.9%	11
6 - 12 months		16.7%	8
over a year		39.6%	19
I have never had a definite diagnosis		6.3%	3
answered question			48
skipped question			2

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		46.8%	22
no		40.4%	19
don't know / don't remember		12.8%	6
Other (please specify)			5
answered question			47
skipped question			3

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		74.5%	35
no		23.4%	11
don't know / don't remember		2.1%	1
answered question			47
skipped question			3

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

		Response Percent	Response Count
yes		12.5%	6
no		85.4%	41
don't know / don't remember		2.1%	1
answered question			48
skipped question			2

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

		Response Percent	Response Count
yes		44.9%	22
no		49.0%	24
don't know / don't remember		6.1%	3
answered question			49
skipped question			1




















11. Why was this?

		Response Percent	Response Count
treatment for my condition was not available		66.7%	16
treatment for my condition was not required		33.3%	8
I refused treatment		0.0%	0
answered question			24
skipped question			26

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		31.9%	15
no		57.4%	27
don't know / don't remember		10.6%	5
answered question			47
skipped question			3

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

		Response Percent	Response Count
physiotherapist		37.8%	17
occupational therapist		26.7%	12
GP		71.1%	32
community nurse		15.6%	7
speech and language therapist		17.8%	8
dietician		11.1%	5
continence nurse		8.9%	4
social services		22.2%	10
care manager		11.1%	5
voluntary organisation/charity		37.8%	17
community matron		0.0%	0
specialist nurse/co-ordinator		22.2%	10
neurologist / consultant / elderly care consultant		33.3%	15
neurosurgeon		6.7%	3
hospice		8.9%	4
psychologist		11.1%	5
intensive care staff		2.2%	1
tissue viability nurse		4.4%	2
orthotist		8.9%	4
mental health worker		0.0%	0
none		11.1%	5

Other (please specify) 11

answered question 45

skipped question

5

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

		Response Percent	Response Count
yes		46.8%	22
no		27.7%	13
don't know		25.5%	12
		answered question	47
		skipped question	3

15. Please say which ones

	Response Count
	17
answered question	17
skipped question	33





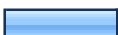














16. Overall, do you feel that the way services are provided are based around your needs rather than the needs of the professional or the services?

		Response Percent	Response Count
yes		8.9%	4
mostly		26.7%	12
partly		17.8%	8
no		31.1%	14
don't know		15.6%	7
		answered question	45
		skipped question	5

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

		Response Percent	Response Count
yes		28.2%	11
no		23.1%	9
don't know		48.7%	19
answered question			39
skipped question			11

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

		Response Percent	Response Count
physiotherapist		35.7%	10
occupational therapist		21.4%	6
GP		71.4%	20
community nurse		14.3%	4
speech and language therapist		17.9%	5
dietician		10.7%	3
continence nurse		7.1%	2
social services		25.0%	7
care manager		7.1%	2
voluntary organisation/charity		28.6%	8
community matron		0.0%	0
specialist nurse/co-ordinator		21.4%	6
neurologist		7.1%	2
neurosurgeon		0.0%	0
hospice		10.7%	3
psychologist		3.6%	1
intensive care staff		3.6%	1
tissue viability nurse		3.6%	1
orthotist		3.6%	1
mental health worker		7.1%	2
none		10.7%	3

Other (please specify) 8

answered question 28

skipped question 22








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

		Response Percent	Response Count
yes		28.6%	12
no		14.3%	6
don't know		57.1%	24
answered question			42
skipped question			8

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		30.2%	13
no		55.8%	24
don't know		14.0%	6
answered question			43
skipped question			7

21. Who is this?

		Response Percent	Response Count
physiotherapist		10.0%	1
occupational therapist		30.0%	3
GP		20.0%	2
community Nurse		10.0%	1
speech and language therapist		0.0%	0
dietician		0.0%	0
continence nurse		0.0%	0
social services		40.0%	4
care manager		0.0%	0
voluntary organisation/charity		0.0%	0
community matron		0.0%	0
specialist nurse/co-ordinator		20.0%	2
neurologist		0.0%	0
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		10.0%	1

Other (please specify) 5

answered question 10

skipped question 40

22. Do you use both health and social services?

		Response Percent	Response Count
yes		26.2%	11
no		61.9%	26
don't know		11.9%	5
answered question			42
skipped question			8

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		63.6%	7
no		0.0%	0
don't know / don't remember		36.4%	4
answered question			11
skipped question			39

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		9.1%	1
mostly		36.4%	4
sometimes		36.4%	4
no		18.2%	2
don't know		0.0%	0
answered question			11
skipped question			39





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

		Response Percent	Response Count
yes		31.0%	13
no		69.0%	29




If yes, please say who e,g Physiotherapist, Consultant Neurologist: 13

answered question			42
skipped question			8

26. Please say why you paid privately

		Response Percent	Response Count
for a second opinion		0.0%	0
didn't like the professional I was referred to		9.1%	1
had to wait too long		54.5%	6
to speed up my diagnosis		9.1%	1
had health insurance		36.4%	4
Other reason - please state:			4
answered question			11
skipped question			39

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

		Response Percent	Response Count
yes		7.7%	1
no		53.8%	7
don't know / don't remember		0.0%	0
not applicable		38.5%	5
answered question			13
skipped question			37

28. Have you accepted?

		Response Percent	Response Count
yes		20.0%	1
no		80.0%	4
answered question			5
skipped question			45

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		23.8%	10
no		76.2%	32
answered question			42
skipped question			8

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		11.9%	5
no		76.2%	32
don't know		11.9%	5
answered question			42
skipped question			8

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			45

32. Is your care plan regularly reviewed?

		Response Percent	Response Count
yes		100.0%	5
no		0.0%	0
only if there is a change in my condition		0.0%	0
answered question			5
skipped question			45

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

		Response Percent	Response Count
yes		19.5%	8
no		53.7%	22
yes, but didn't want any information at the time.		9.8%	4
don't know / don't remember		17.1%	7
answered question			41
skipped question			9

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		12.2%	5
no		65.9%	27
yes, but didn't want any information at the time.		4.9%	2
don't know / don't remember		17.1%	7
answered question			41
skipped question			9

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		17.1%	7
no		68.3%	28
yes, but didn't want any information at the time.		2.4%	1
don't know / don't remember		12.2%	5
answered question			41
skipped question			9







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		7.3%	3
sometimes		19.5%	8
no		61.0%	25
not currently applicable		12.2%	5
answered question			41
skipped question			9






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

		Response Percent	Response Count
yes		14.6%	6
no		51.2%	21
I do not want any information		0.0%	0
don't know		34.1%	14
answered question			41
skipped question			9

**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		2.6%	1
GP		31.6%	12
consultant neurologist or other doctors		13.2%	5
other health and social care staff that you deal with		21.1%	8
internet search		55.3%	21
voluntary organisations		65.8%	25
	Other (please specify)		5
answered question			38
skipped question			12

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		12.5%	5
mostly		20.0%	8
not very often		27.5%	11
no		35.0%	14
not applicable		5.0%	2
answered question			40
skipped question			10

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		9.8%	4
mostly		22.0%	9
not very often		29.3%	12
no		31.7%	13
not applicable		7.3%	3
answered question			41
skipped question			9

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

		Response Percent	Response Count
yes		17.1%	7
mostly		36.6%	15
not very often		14.6%	6
no		22.0%	9
not applicable		9.8%	4
answered question			41
skipped question			9

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

		Response Percent	Response Count
yes		26.2%	11
no		73.8%	31
answered question			42
skipped question			8






43. What type of care did you receive?

		Response Percent	Response Count
immediate and appropriate treatment on a neurological ward		20.0%	2
immediate and appropriate treatment on a general ward		50.0%	5
inappropriate and unsatisfactory treatment on a general ward		30.0%	3
inappropriate or unsatisfactory treatment on a neurological ward		0.0%	0
answered question			10
skipped question			40






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		31.0%	13
no		69.0%	29
answered question			42
skipped question			8

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		9.8%	4
yes, but declined		4.9%	2
no		63.4%	26
no, not applicable		17.1%	7
can't remember		4.9%	2
answered question			41
skipped question			9

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		9.8%	4
yes, but declined		2.4%	1
no		61.0%	25
no, not applicable		24.4%	10
can't remember		2.4%	1
answered question			41
skipped question			9

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		45.2%	19
no		54.8%	23
	If yes (please specify)		18
	answered question		42
	skipped question		8

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

		Response Percent	Response Count
yes		10.5%	2
no		42.1%	8
to some extent		36.8%	7
don't know / don't remember		10.5%	2
	answered question		19
	skipped question		31






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		31.6%	6
no		36.8%	7
to some extent		10.5%	2
don't know / don't remember		21.1%	4
answered question			19
skipped question			31



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

		Response Percent	Response Count
yes		15.8%	3
no		52.6%	10
don't know / don't remember		31.6%	6
answered question			19
skipped question			31



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

		Response Percent	Response Count
yes - retirement on medical grounds		33.3%	14
yes - voluntarily		21.4%	9
no		14.3%	6
no - but I have changed from full-time to part-time employment		11.9%	5
not applicable - was not in paid employment / was retired		19.0%	8
answered question			42
skipped question			8

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		50.0%	15
no		50.0%	15
answered question			30
skipped question			20

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		42.9%	6
no		57.1%	8
answered question			14
skipped question			36

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		30.0%	12
no		70.0%	28
answered question			40
skipped question			10

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

		Response Percent	Response Count
yes		66.7%	8
no		33.3%	4
can't remember		0.0%	0
answered question			12
skipped question			38

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

		Response Percent	Response Count
yes		14.3%	1
no		85.7%	6

If yes, please say, if you can, which ones and approximately how long you waited? 2

answered question			7
skipped question			43

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

		Response Percent	Response Count
yes		57.5%	23
no		27.5%	11
not needed any		15.0%	6
answered question			40
skipped question			10

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

		Response Percent	Response Count
yes		47.8%	11
no		43.5%	10
don't know		8.7%	2
answered question			23
skipped question			27

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		15.0%	6
no		52.5%	21
no, but I feel I need some help		32.5%	13
answered question			40
skipped question			10

60. Is this arranged by social services?

		Response Percent	Response Count
yes		33.3%	2
no		66.7%	4
answered question			6
skipped question			44

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		80.0%	4
no		0.0%	0
mostly		20.0%	1
to some extent		0.0%	0
What changes, if any, would you want to make?			3
answered question			5
skipped question			45

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		30.0%	12
no		70.0%	28
answered question			40
skipped question			10

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

		Response Percent	Response Count
yes		0.0%	0
no		100.0%	12
If yes, please say which ones:			0
answered question			12
skipped question			38

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		25.0%	10
no		75.0%	30
answered question			40
skipped question			10

65. Are you on a waiting list to move?

		Response Percent	Response Count
yes		0.0%	0
no		100.0%	10
answered question			10
skipped question			40

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		0.0%	0
1 - 2 years		0.0%	0
more than 2 years		0.0%	0
answered question			0
skipped question			50

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		25.6%	10
yes - spouse/partner		56.4%	22
yes - relative		17.9%	7
yes - friend		0.0%	0
other (please specify)			3
answered question			39
skipped question			11

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

		Response Percent	Response Count
yes		10.3%	4
no		41.0%	16
yes , but they didn't want it		2.6%	1
don't know / don't remember		7.7%	3
not applicable		38.5%	15
answered question			39
skipped question			11

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

		Response Percent	Response Count
yes		15.4%	6
no		38.5%	15
yes , but they didn't want it		2.6%	1
don't know / don't remember		5.1%	2
not applicable		38.5%	15
answered question			39
skipped question			11

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

		Response Percent	Response Count
always		2.6%	1
mostly		23.1%	9
sometimes		17.9%	7
never		17.9%	7
not applicable		38.5%	15
answered question			39
skipped question			11





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

	Response Count
	29
answered question	29
skipped question	21

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

	Response Count
	25
answered question	25
skipped question	25

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		17.1%	6
got worse		17.1%	6
stayed about the same		40.0%	14
not sure whether or not they've changed		25.7%	9

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

answered question 35

skipped question 15

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

		Response Percent	Response Count
yes		54.1%	20
no		16.2%	6
don't know		29.7%	11

If yes could you give examples? 18

answered question 37

skipped question 13

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

		Response Percent	Response Count
yes		43.2%	16
no		5.4%	2
don't know		51.4%	19

If yes could you give examples? 13

answered question	37
skipped question	13

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

	Response Count
	28
answered question	28
skipped question	22

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	42