

A large, stylized graphic element consisting of several overlapping, rounded triangular shapes in various shades of orange and yellow, creating a sense of depth and movement. The central text is placed within one of these shapes.

Neurology Now - 2021
Impact of COVID-19 for
people with MS - data tables

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August 2021

Let's stop MS **together**

Introduction

This report provides a selection of data tables to support the UK wide report Neurology Now.

We conducted a survey of 746 people across the UK with MS between 17 -31 August 2021. With this, we wanted to understand the impact of the pandemic on neurological services and people living with MS in the UK.

In this survey 83% of respondents were from England, 6% from Scotland, 4% from Wales, 3% from Northern Ireland and for 4% their location was unknown. 76% of respondent's women and 24% were men. The majority of respondents (67%) were aged between 55 and 74 years old, 18% being 45 and 54 years old and 9% being 75 years old or older. Those aged younger than 34 years was 2.3%.

Note on data tables

The title of each table is directly comparable to the format in which the question was asked in the survey. Except in the case where two questions have been crossed for comparison. In these cases the title of the table is representative of the data shown.

Where the question was single answer the total sample size is denoted by 'Total' at the bottom of the table. Where respondents were able to select more than one response the total sample size is denoted at the bottom of the table by 'total respondents'. In these instances the percentages may not sum to 100%.

Some of the figures cited in this report are the proportion of people with a given need who said that this need was met. This is the number of people who answered 'Yes' to a specific question, divided by the number of people who answered either 'Yes' or 'No, but I needed to'.

Where straight proportions of a single question are presented these are accompanied by the 95% confidence interval (CI). The first number is the lower and the second number is the upper confidence.

Data tables

What type of MS do you have?

	Percent	Responses	CI
Relapsing remitting	39%	292	35-42%
Secondary progressive with relapses	13%	98	10-15%
Secondary progressive without relapses	25%	188	22-28%
Primary progressive	18%	132	15-20%
Unknown	5%	36	3-6%
Total	100%	746	

What best describes your gender?

	Percent	Responses	CI
Female	76%	564	72-79%
Male	24%	182	21-27%
Total	100%	746	

How old are you? (Years)

	Percent	Responses	CI
25-34 years	2%	17	1-3%
35-44 years	4%	33	3-6%
45-54 years	35%	258	31-38%
65-74 years	32%	238	28-35%
75-84 years	8%	60	6-10%
85 or over	1%	7	0-2%
Total	100%	746	

What is your religion/ belief?

	Percent	Responses	CI
Agnostic	5%	40	39-72%
Buddhist	1%	4	0-1%
Christian	60%	450	57-64%
Hindu	0.3%	1	0-1%
Jewish	1%	6	0-1%
Muslim	0.3%	2	0-1%
No religion/Atheist	26.5%	198	24-30%
Other	1.3%	10	1-2%
Prefer not to say	4.7%	35	3-6%
Total	100%	746	

Where do you live?

	Percent	Responses	CI
East Midlands	8%	60	6-10%
East of England	9%	64	7-11%
Greater London	6%	42	4-8%
Greater Manchester	2%	14	1-3%
North East	11%	80	9-13%
North West	11%	81	9-13%
Northern Ireland	3%	22	1-4%
West Midlands	6%	43	4-8%
Scotland	6%	44	4-8%
South East	17%	128	15-20%
South West	13%	96	11-15%
Wales	4%	29	3-6%
West Midlands	2%	12	0-3%
Outside the UK	0.3%	2	0-1%
Prefer not to answer	3.9%	29	2-6%
Total	100%	746	

What ethnic group do you identify with?

	Percent	Responses	CI
Asian/Asian British	1%	6	0-1%
Black/African/Caribbean/Black British	1%	6	0-1%
Mixed/Multiple Ethnic Groups	1%	7	0-1%
Other Ethnic Group	1%	4	0-1%
White	95%	706	93-96%
Other	1%	9	0-1%
Prefer not to say	1%	8	0-2%
Total	100%	746	

How long ago were you diagnosed with MS by your neurologist?

	Percent	Responses	CI
Less than 12 months ago	1%	9	0-2%
1-5 years ago	7%	53	5-9%
6-10 years ago	13%	97	11-16%
11-20 years ago	35%	261	32-38%
21-50 years ago	43%	317	39-46%
More than 50 years ago	1%	8	0-2%
I don't know	0.1%	1	0-1%
Total	100%	746	

In the past 12 months, have you seen an MS specialist nurse in relation to your MS?

	Percent	Responses	CI
Yes	39%	291	36-43%
No, and I have not needed to	36%	268	33-39%
No, but I needed to	24%	175	21-27%
I am not sure	2%	12	0-2%
Total	100%	746	

Where did you meet your MS specialist nurse?

	Percent	Responses	CI
In a specialist hospital setting	32%	93	23-32%
In an outreach clinic	5%	15	3-7%
In a community setting	.3%	1	0-1%
In your home	9%	27	5-11%
By telephone	56%	165	51-62%
By email	5%	15	3-8%
By video call	8%	24	5-12%
Other	1%	4	0-1%
Total	116%	344	

In the past 12 months, have you seen a neurologist in relation to your MS?

	Percent	Responses	CI
Yes	34%	255	31-38%
No, and I have not needed to	39%	289	35-42%
No, but I needed to	26%	192	23-29%
I am not sure	1%	10	0-2%
Total	100%	746	

Where did you meet with your neurologist?

	Percent	Responses	CI
In a specialist hospital setting	41%	105	35-47%
In an outreach clinic	4%	9	2-6%
In your home	1%	3	0-1%
By telephone	50%	127	44-56%
By email	1%	3	0-1%
By video call	12%	30	8-16%
Other	2%	5	1-4%
Total	111%	282	

In the past 12 months, have you seen a specialist about continence advice in relation to your MS? (E.g. bladder or bowel advice)

	Percent	Responses	CI
Yes	21%	158	18-24%
No, and I have not needed to	56%	416	52-59%
No, but I needed to	21%	158	18-24%
I am not sure/ prefer not to say	2%	14	1-3%
Total	100%	746	

In the past 12 months, have you received support for mood or emotional issues? (E.g. from health or community services rather than friends or family)

	Percent	Responses	CI
Yes from the NHS	11%	80	8-13%
Yes from a charity or voluntary organisation	3%	20	1-4%
Yes from a private company or individual	3%	24	2-5%
Yes from somewhere else	3%	24	2-5%
Yes, but I needed more support	3%	23	2-5%
No, and I have not needed support	60%	447	54-61%
No, but I needed support	20%	150	17-22%
I am not sure	1%	6	0-2%
Total	104%	774	

In the past 12 months, have you seen a physiotherapist in relation to your MS?

	Percent	Responses	CI
Yes from the NHS	18%	132	14-20%
Yes from a charity or voluntary organisation	5%	39	4-7%
Yes from a private company or individual	8%	59	6-10%
Yes from somewhere else	1%	10	0-2%
Yes, but I needed more support	4%	27	2-5%
No, and I have not needed support	42%	314	37-44%
No, but I needed support	26%	195	22-28%
I am not sure	1%	7	0-2%
Total	105%	783	

In the past 12 months, have you received information on how to self-manage your symptoms/ condition? (Question only open to those who have had appointments cancelled or delayed, had to wait a long time, have not been able to speak to an MS Specialist when needed).

	Percent	Responses	CI
Yes and I found it very helpful	3%	10	2-6%
Yes, I found it somewhat helpful	15%	42	11-19%
No, but I would have liked to	51%	147	45-56%
No but I didn't want to	27%	79	22-33%
I'm not sure	4%	11	2-7%
Total	100%	289	

Below is a list of disease-modifying therapies that are licensed specifically for MS at present. Please select from the list which drug you are currently taking:

	Percent	Responses	CI
Aubagio (Teriflunomide)	1%	8	0-2%
Avonex (beta interferon 1a)	3%	19	2-4%
Betaferon (beta interferon 1b)	1%	10	0-2%
Copaxone (glatiramer acetate)	6%	45	4-8%
Gilenya (fingolimod)	4%	28	3-5%
Lemtrada (Alemtuzumab)	1%	9	0-2%
Plegridy (peginterferon beta 1a)	2%	12	0-3%
Rebif (beta interferon 1a)	1%	10	0-2%
Tecfidera (Dimethyl fumerate)	7%	52	5-9%
Tysabri (natalizumab)	3%	21	2-4%
Mavenclad (Cladribine)	1%	5	0-1%
Ocrevus (Ocrelizumab)	3%	19	2-4%
Ofatumumab (Kesimpta)	0.3%	2	0-1%
Not applicable	68%	509	65-71%
Total	101%	749	

Have you experienced any of the following in the past 12 months?
Tick all that apply

	Percent	Responses	CI
I was told my treatment was delayed because of the impact of COVID-19 on my MS service	10%	71	7-11%
I decided not to start treatment because of COVID-19	1%	4	0-1%
I decided to delay starting treatment because of COVID-19	1%	9	0-2%
I decided to change from one treatment to another because of COVID-19	0%	2	0-1%
I decided to stop treatment because of COVID-19	0%	2	0-1%
I was told I couldn't start the treatment I preferred because of COVID-19	2%	15	1-3%
Not applicable, I am not currently taking a DMT	48%	360	43-50%
None of the above	42%	313	37-44%
Total	104%	776	

Thinking about your support needs as a whole (practical, emotional, financial etc.) which of the following statements best describes your situation?

	Percent	Responses	CI
I don't need support	11%	81	9-13%
I feel I have the support I need	37%	274	33-40%
I feel I have some of the support I need but not enough	34%	256	31-38%
I don't have the support I need	12%	89	10-14%
Not sure	6%	46	5-8%
Total	100%	746	

In the past 12 months, have you received support so that you can keep physically active? (E.g. help to attend exercise classes, or use sport facilities and leisure facilities.)

	Percent	Responses	CI
Yes from the NHS	6%	42	4-7%
Yes from a charity or voluntary organisation	12%	91	9-13%
Yes from a private company or individual	6%	44	4-7%
Yes I/ my family paid for it	8%	58	6-9%
Yes, from somewhere else	5%	40	4-7%
Yes, but I needed more support	4%	29	2-5%
No, and I have not needed support	38%	287	32-38%
No, but I needed support	28%	212	23-29%
I am not sure	2%	14	1-3%
Total	109%	817	

How has the pandemic impacted your access to MS services? Tick all that apply.

	Percent	Responses	CI
I've had appointments by phone or video call	67%	500	64-70%
I've not asked for the help I needed from MS healthcare services because I thought they were busy	9%	68	7-11%
I've had appointments cancelled or delayed	29%	216	26-32%
I've cancelled or delayed appointments due to concerns about infection	4%	27	2-5%
I've had to wait a long time	13%	94	10-15%
I have not been able to speak to an MS specialist when I needed to	12%	89	9-14%
No impact I haven't needed to access any services for my MS	11%	81	8-13%
No impact, I've been able to access services I needed	11%	78	8-13%
Don't know	2%	11	0-2%
Other	7%	50	5-9%
Total	165%	1214	

Thinking about appointments you have attended by video or telephone, do you feel you got enough support?

	Percent	Responses	CI
Yes, I received all of the support and information I needed	38%	289	35-42%
I received some support and information I needed but not all	27%	206	25-31%
No, I didn't receive the support and information I needed	13%	103	12-16%
Other - Write In	4%	27	2-5%
I didn't have any video or telephone calls	16%	121	14-19%
Total	98%	746	

Do you feel your MS symptoms have changed since the beginning of the pandemic?

	Percent	Responses	CI
My symptoms have improved since before the pandemic	2.0%	13	1-3%
My symptoms have got worse but this was expected due to the nature/ stage of my MS	32%	237	29-35%
My symptoms have unexpectedly got worse since the start of the pandemic	20%	147	17-23%
I feel much the same as I did before the pandemic	37%	274	33-40%
I'm not sure	6%	47	5-8%
Other	4%	28	3-5%
Total	101%	746	

Comparison of people taking DMT's and the proportion with a change in symptoms

	Percent	Responses	CI
My symptoms have improved since before the pandemic	3%	8	2-6%
My symptoms have got worse but this was expected due to the nature/ stage of my MS	19%	45	14-24%
My symptoms have unexpectedly got worse since the start of the pandemic	20%	47	15-25%
I feel much the same as I did before the pandemic	47%	112	41-53%
I'm not sure	8%	18	5-11%
Other	3%	7	2-6%
Total	100%	237	

To what extent do you think a reduction to the specialist support you received before the pandemic contributed to your symptoms getting worse?

	Percent	Responses	CI
Greatly	11%	43	8-15%
To some extent	42%	161	37-47%
Not at all	25%	97	21-30%
Not applicable, I have not seen a reduction in support	10%	38	7-13%
Not applicable, I didn't receive support before	12%	45	9-15%
Total	100%	384	

Can you identify any MS symptoms which have got worse during the pandemic from the list below? Tick all that apply (Question only open to those reported symptoms getting worse).

	Percent	Responses	CI
Walking or balance	76%	293	72-80%
Fatigue/ tiredness	67%	259	63-72%
Pain	45%	171	40-50%
Muscles in arms and legs feel weaker	58%	222	51-63%
More muscle stiffness or spasms	45%	172	40-50%
Breathing has got worse	12%	44	9-15%
Problems swallowing	15%	57	12-19%
Controlling bladder/ bowel	47%	180	42-52%
Memory and concentration	44%	170	40-49%
Problems sleeping	30%	116	26-35%
Low mood	39%	151	35-44%
Memory and concentration	36%	138	31-41%
I'm less able to care for myself	29%	112	25-34%
I'm not sure	1%	2	0-1%
Other	3%	13	2-6%
Total	547	2100	

Please select any specific areas of health and/ or wellbeing that have been affected by a delay in appointments with MS services and/ or treatments. Tick all that apply

	Percent	Responses	Confidence Interval
Tiredness	24%	179	21-27%
Depression	16%	122	14-19%
Anxiety	19%	142	16-22%
Loss of appetite	3%	19	1-4%
Disturbed or lost sleep	18%	132	15-20%
General feeling of stress or worry	21%	156	18-24%
Physical strain (e.g. back)	13%	93	10-15%
Loneliness	9%	64	7-11%
Spasticity	18%	131	15-20%
Pain	20%	150	17-23%
Mobility	38%	282	34-41%
Overall quality of life	19%	143	17-22%
MS symptoms have got worse	24%	184	22-28%
I have felt socially isolated	14%	102	11-16%
Other health condition has got worse	10%	73	8-12%
None of the above	33%	248	30-37%
Other	6%	45	5-8%
Total	305%	2265	

Have you received support from additional services (charitable organisations, Citizens Advice, private health care) due to delays in appointments with specialist services?

	Percent	Responses	CI
Greatly	2%	17	1-4%
To some extent	15%	108	12-17%
Not at all	58%	429	54-61%
Not applicable, I have not seen a reduction in support	26%	192	23-29%
Total	100%	746	

What type of support did you receive from additional services? Tick all that apply

	Percent	Responses	CI
Physio/ rehabilitation	50%	63	42-59%
Speech and language	3%	4	1-8%
Mental health / emotional	21%	27	15-30%
Diet and nutrition	10%	13	6-17%
Continence	15%	19	10-23%
General information on MS	13%	16	8-20%
Employment	2%	2	0-2%
Financial	8%	10	4-14%
Not sure	5%	6	2-10%
Other	19%	24	13-27%
Total	146%	184	

Comparison of people taking DMT's and the proportion who experienced delays/ cancelled treatment (Tick all that apply)

	Percent	Responses	CI
I was told my treatment was delayed because of the impact of COVID-19 on my MS service	12%	32	10-18%
I decided not to start treatment because of COVID-19	1%	3	0-3%
I decided to delay starting treatment because of COVID-19	2%	6	1-5%
I decided to change from one treatment to another because of COVID-19	0.7%	2	0-3%
I decided to stop treatment because of COVID-19	0.3%	1	0-2%
I was told I couldn't start the treatment I preferred because of COVID-19	6%	15	4-10%
Not applicable, I am not currently taking a DMT	4%	11	3-8%
None of the above	73%	187	73-84%
Total	99%	257	

We're the MS Society.
Our community is here for you
through the highs, lows and
everything in between.
We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk



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Multiple Sclerosis Society.
Registered charity nos. 1139257 / SC041990.
Registered as a limited company by guarantee
in England and Wales 07451571.

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