

# BMJ Open Smoking habits, awareness and support needs for cessation among people with multiple sclerosis in Australia: findings from an online survey

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## ABSTRACT

**Objectives** To assess smoking habits, nicotine use, exposure to passive smoking, awareness of associated harms, and experiences with and preferences for smoking cessation support among people with multiple sclerosis (MS).

**Design** Online survey, convenience sampling.

**Setting** Community setting, Australia.

**Participants** Adults living in Australia with probable or diagnosed MS were recruited via social media and newsletters to participate in 2020.

**Results** Of the 284 participants in our convenience sample, 25.7% were current smokers (n=73) and 38.0% were former smokers (n=108). Awareness of the harms of smoking on MS onset (n=68, 24.3%) and progression (n=116, 41.6%) was low. Almost a quarter (n=67, 23.8%) of participants were regularly exposed to passive smoke, and awareness of associated harm was also low (n=47, 16.8%). Among current smokers, 76.1% (n=54) had tried quitting and 73.2% considered quitting within 6 months (n=52). Many participants reported perceived short-term benefits of smoking, and long-term benefits of quitting, on MS symptoms and general well-being (short-term n=28, 40.0%; long-term n=28, 82.4%). While most participants reported that their neurologist (n=126, 75.4%) or other healthcare providers (n=125, 74.9%) had assessed smoking status, very few neurologists (n=3, 1.8%) or other healthcare providers (n=14, 8.4%) had provided help with quitting. Most current smokers preferred speaking about smoking to a neurologist (n=36, 52.2%) or general practitioner (n=41, 59.4%). Almost 60% of the current smokers wanted additional cessation information specific to MS (n=41, 59.4%), and 45.5% said this information would motivate them to quit smoking (n=30).

**Conclusions** Our convenience sample, which may not be representative, indicated an urgent need for regular evidence-based smoking cessation supports for people with MS. Most participants felt they would benefit from smoking cessation advice. MS clinicians, in collaboration with patient organisations, smoking cessation services and general practitioners, should make smoking cessation promotion with people with MS a priority.

## INTRODUCTION

Current evidence indicates that genetic and environmental factors contribute to multiple

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study expands on perspectives of people with multiple sclerosis (MS) in relation to what and when smoking cessation information is provided, enabling targeted time-critical support.
- ⇒ There is potential for bias related to self-selection in the study, which could lead to an overestimation of the prevalence of smoking, but underestimate the lack of knowledge about the relationship between MS and smoking.
- ⇒ Furthermore, the lack of a prespecified target sample and the inability to calculate a response rate or assess non-response bias, due to the sampling method, limit the generalisability of the study.
- ⇒ Reporting past quit attempts and healthcare professionals' advice may be subject to recall bias.
- ⇒ Caution should be taken in generalising to other countries beyond Australia, as knowledge gaps and related concerns may be worse in countries where there is less focus on tobacco control.

sclerosis (MS) risk,<sup>1</sup> and tobacco smoking has been identified as a key modifiable risk factor.<sup>2</sup> Smoking tobacco presents considerable health risks to people diagnosed with MS,<sup>3</sup> with evidence for a causal association between smoking and MS progression.<sup>4–6</sup> Furthermore, studies in people with MS report associations between tobacco smoking and worse fatigue, depressive symptoms and health-related quality of life<sup>7</sup>; higher relapse rate during interferon beta treatment<sup>8</sup> and natalizumab treatment<sup>9</sup>; more comorbidities such as heart disease<sup>10</sup>; and higher premature mortality.<sup>11</sup>

Evidence is emerging that people with MS are largely unaware of the risks of smoking to MS, and that there are MS-specific barriers to quitting, such as the potential impact of cessation-induced stress on MS.<sup>12–14</sup> Our qualitative work also identified several MS-specific barriers to smoking cessation, including concerns that quitting may negatively impact

MS symptoms, such as mood, cognition, pain and relapses.<sup>14</sup> Some participants were also unsure whether nicotine replacement therapy (NRT) or other cessation medications would be safe to use for people with MS, or in combination with common MS medication, an indication that needs of people with MS in relation to smoking cessation were not met.<sup>14</sup>

The current study aimed to assess whether people with MS (regardless of smoking status) were aware of the links between smoking, including passive smoking and MS. Furthermore, we aimed to quantitatively assess smoking habits, motivators for smoking, barriers and facilitators to smoking cessation, and cessation preferences of people with MS who were current or former smokers. If there are MS-specific barriers to cessation, a lack of tailored support and information that goes beyond tools designed for the general population is likely to mean less successful cessation.<sup>3</sup>

## METHODS

### Reporting standards and participant consent

This study conforms to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cross-sectional studies and the Checklist for Reporting Of Survey Studies (CROSS) (online supplemental files 1; 2).<sup>15 16</sup> Participants provided digital consent before entering the survey. Responses were recorded confidentially in Qualtrics, and the data files stored in a password protected folder on a secure university server. Participant data were deidentified for analyses.

### Participants and recruitment

People living in Australia aged 18 years and older with probable (neurologist-diagnosed clinically isolated syndrome or first demyelinating event) or diagnosed MS were invited to participate via websites, newsletters and social media channels of relevant organisations in Australia (MS Australia, MS Research Australia and the MS state societies) and MS support groups. Data were collected over 11 weeks between May and July 2020.

### Survey

The survey consisted of approximately 75 questions, with a mix of multiple-choice, matrix table and text entry questions, using display logic to direct participants to relevant questions consistent with previous responses using the platform Qualtrics (online supplemental file 3).

The survey collected demographic and clinical information including level of disability using the Patient Disability Disease Steps.<sup>17</sup> Remoteness of residential location was derived from postcodes.<sup>18</sup> Participants were asked about smoking habits, knowledge of and experience with smoking, passive smoking, smoking cessation, nicotine products, interactions with healthcare providers regarding smoking-related topics and preferences for smoking cessation support.

### Data analysis

Stata/SE V.16.1 was used for all analyses.<sup>19</sup> Descriptive statistics are presented for survey responses, stratified by smoking status when relevant. Median and IQR were calculated for continuous variables that were not normally distributed. In some instances where several multiple-choice options were offered, categories were combined for presentation in the results. Integrity of the data was checked to identify and remove ineligible participants, bots (automatically flagged by Qualtrics), duplicate responses or mostly incomplete responses (less than 20% of survey items). We conducted a complete case analysis, and percentages were calculated based on the number of participants that completed that item, reported in each section.

### Patient and public involvement

The survey instrument was constructed from the results of previous in-depth qualitative interviews assessing the perspectives of 25 people with MS who were current or recent smokers<sup>14</sup> and research team expertise, which included a person with MS, a former smoker, smoking cessation experts, MS researchers, clinicians and cessation advocates. Some survey items were based on other relevant surveys and literature.<sup>20–23</sup> Four volunteers not involved in the study pilot-tested the survey.

## RESULTS

After removing 29 records (n=1 bot; n=1 duplicate; n=2 did not consent to participate; n=3 did not have either definite or probable MS; n=22 exited survey before completing 20% of survey questions), the final convenience sample comprised 284 participants, 90.1% of whom completed all survey questions relevant to them (n=256).

### Demographic and clinical information

Most participants were women (n=250, 88.0%), and the median age was 46 (IQR 38–56.5, range 18–76 years). Almost all participants reported a neurologist-confirmed diagnosis of definite MS (n=278, 97.9%) and median years since diagnosis was 7 years (IQR 2–16, range 0–39 years). Other characteristics are reported in [table 1](#).

### Awareness of the relationship between smoking and MS

Most participants were unaware of the associations between smoking and MS onset, progression or treatment ([table 2](#)). Those 150 participants who were aware of at least one of the risks were asked how they obtained this information. The most common sources for this information were MS healthcare providers (n=64, 42.7%), online information (n=54, 36.0%), MS societies (n=40, 26.7%), guessing (n=27, 18.0%), general practitioner (n=14, 9.3%), family member or friend (n=6, 4.0%) and other (n=19, 12.7%).

### Smoking habits and nicotine use

As reported in [table 3](#), 73 participants were current smokers (25.7%) (67 daily, 6 weekly) and 38.0% were

**Table 1** Demographic and clinical information

	n	%
Total	284	100.0
Gender		
Women	250	88.0
Men	33	11.6
Non-conforming*	1	0.4
Age (years)		
18–29	26	9.2
30–39	64	22.5
40–49	79	27.8
50–64	95	33.5
65 and over	20	7.0
Education		
High school	66	23.2
Diploma or technical qualification	82	28.9
University degree	136	47.9
State of residence†		
New South Wales	68	24.0
Australian Capital Territory	12	4.2
Victoria	99	35.0
Queensland	25	8.8
South Australia	32	11.3
Western Australia	33	11.7
Tasmania	13	4.6
Northern Territory	1	0.4
Remoteness‡		
Major cities	204	72.3
Inner regional	62	22.0
Outer regional and remote	16	5.7
Main activity†		
Full-time employment	91	32.2
Part-time employment	69	24.4
Study, home or carer duties	32	11.3
Currently look for work, or other	21	7.4
Retirement	70	24.7
Disease duration§		
0–2 years	70	25.2
3–5 years	49	17.6
6–10 years	44	15.8
11–15 years	40	14.4
16 years or longer	75	27.0
MS subtype§		
Relapsing-remitting MS	211	75.9
Secondary progressive MS	40	14.4
Primary progressive MS	13	4.7
Other/unknown	14	5.0

Continued

**Table 1** Continued

	n	%
Level of disability§		
No disability	81	29.1
Mild/moderate disability	91	32.7
Gait/cane disability	76	27.3
Bilateral support/wheelchair/scooter	30	10.8
Neurology care¶		
Private neurologist	117	42.5
Public neurologist	151	54.9
Not regularly seeing a neurologist	7	2.5
*Text entry by participant.		
†Missing data n=1.		
‡Missing data n=2.		
§Clinical variables include participants with definite MS only, no missing data.		
¶Missing data=9.		
MS, multiple sclerosis.		

former smokers (n=108). Use of nicotine vaping products (n=14, 7.8%) and NRT (n=12, 6.7%) was reported by 23.6% of the current smokers (n=17) and 8.3% of former smokers (n=9), but none of the never smokers. Almost half of the current smokers (n=31, 43.7%) and 17.1% of non-smokers (n=36) reported being exposed to passive smoke regularly, while 10.0% of non-smokers (n=21) and 39.4% of smokers (n=28) lived with someone who smoked.

Of those (n=43) current and former smokers who made a quit attempt in the past 2 years, less than half used NRT (n=20, 46.5%), while some used other stop-smoking medication (n=12, 27.9%), advice from healthcare provider (n=12, 27.9%), internet sites for quitting advice and support (n=10, 23.3%), or mobile phone-based programmes (n=9, 20.9%). Only 18.6% indicated they quit without any cessation support (n=8). Most current smokers reported attempts to quit in the past (n=54, 76.1%), and 28.2% reported attempts to quit in the past 12 months (n=20). Quit attempts commonly lasted less than 1 month in duration (n=24, 44.4%).

### Motivators to continue smoking

Almost all current smokers (n=72, 1 missing) reported to smoke to cope with stress (n=51, 70.8%), to have time out/a break (n=44, 61.1%), for enjoyment (n=35, 48.6%), as a distraction (n=25, 34.7%), for something to do when their mood is low (n=25, 34.7%), and to prevent nicotine withdrawal symptoms (n=22, 30.6%). Some reported smoking for something to do when isolated (n=16, 22.2%), because their partner or other person in their household smokes (n=10, 13.9%), to cope with MS symptoms (n=9, 12.5%) or for something to do when unable to work (n=6, 8.3%).

**Table 2** Awareness of associations between smoking and MS

		Do not know	More likely	Less likely	Makes no difference
Do you think people who smoke are more or less likely to get MS?*	n	113	<b>68</b>	0	99
	%	40.4	<b>24.3</b>	0	35.4
Do you think people who breathe in secondhand smoke are more or less likely to get MS?†	n	127	47	4	101
	%	45.5	16.8	1.4	36.2
Do you think that smoking has an impact on MS relapses?‡	n	125	107	3	44
	%	44.8	38.4	1.1	15.8
Do you think that smoking has a long-term impact on the progression of MS?†	n	133	<b>116</b>	0	30
	%	47.7	<b>41.6</b>	0	10.8
Do you think that smoking has an impact on MS medications?‡	n	217	34	0	27
	%	78.1	12.2	0	9.7

\*n=280  
†n=279.  
‡n=278.  
MS, multiple sclerosis.

### Readiness and motivators to quit

Of the 71 current smokers, 21.1% considered quitting in the next 30 days (n=15), and an additional 52.1% in the next 6 months (n=37). Their motivators to quit included to improve general health (n=50, 96.2%), MS or MS symptoms (n=30, 57.7%), for financial reasons (n=27, 51.9%), and for family, partner and friends (n=17, 32.7%), and social pressure (n=7, 13.5%). Some current smokers were not seriously thinking of quitting in the next 6 months (n=10, 14.1%) and some were not at all interested in quitting (n=9, 12.7%).

### Changes in symptoms and well-being from smoking or cessation

Current smokers were asked whether they noticed short-term changes in symptoms or well-being immediately after smoking, reported in table 4. Of the 71 current smokers who reported concerns regarding smoking cessation, most cited negative effects on mood (n=43, 60.6%), and the process being too stressful (n=38, 53.5%) and difficult (scared they could not quit) (n=35, 49.3%), an increase in boredom (n=20, 28.2%), side effects of quitting medications (n=15, 21.1%), an MS relapse due to the stress of quitting (n=14, 19.7%), worsening of symptoms (n=10, 14.1%), and smoking cessation medications interfering with MS medication (n=10, 14.1%). Participants who had ever quit smoking for more than 4 weeks reported overall improvements in symptoms (table 5).

### Healthcare providers and cessation support

Among current smokers with a current neurologist (n=67), only one participant reported that their neurologist had provided assessment, advice as well as support with quitting (table 6). A lower proportion of the current smokers reported that their private neurologist assessed their smoking status (n=21, 80.8%) and advised to quit (n=10, 38.5%), compared with those visiting public neurologists (asked about smoking status: n=39, 95.1%,

advised to quit: n=25, 61.0%). Of the current smokers with a neurologist, 77.6% reported that their neurologist was aware of their smoking status (n=52). Of the current smokers who were seeing health professionals other than MS clinicians, 85.3% reported that their general practitioner was aware of their smoking status (n=58).

Of the current and former smokers, 28.1% reported that they were satisfied with the cessation support that they received from their healthcare providers (n=47) (similar for current vs former smokers). More than one-third of the current smokers reported that they would feel disappointed if none of their healthcare providers discussed smoking with them (n=26, 38.2%), some would feel relieved (n=9, 13.2%) and the rest selected a neutral response (n=32, 47.1%).

### Preferences for smoking cessation support

Most current smokers (n=69, 4 missing) reported a preference to speak about smoking with their general practitioner (n=41, 59.4%) or neurologist (n=36, 52.2%), with fewer mentioning an MS nurse (n=24, 34.8%) and a pharmacist (n=12, 17.4%). Only 5.8% preferred not to speak with any healthcare provider (n=4). Half of the current smokers ranked the importance of receiving cessation support from people with knowledge about MS as extremely or very important (n=34, 50.7%).

Of the current smokers, more than half reported that they need additional cessation information specific to MS (n=41, 59.4%) (regardless of readiness to quit). If current smokers were to receive information about the MS-related benefits of quitting, 45.5% reported they would be motivated to quit smoking (n=30) and an additional 19.7% would be motivated to reduce smoking (n=13). However, 19.7% reported that such information would not affect their smoking habits (n=13), and a small proportion expected that such information would elicit guilt and stress, causing them to smoke more (n=8,



**Table 3** Smoking habits, nicotine use and exposure to passive smoke

Variable	Respondents	Category	n	%
Smoking status	All participants	Current daily or weekly	73	25.7
		Former daily or weekly	108	38.0
		Never smoked daily or weekly	103	36.3
Using other nicotine products	All participants*	Yes	26	9.2
		No	257	90.8
Exposure to passive smoking	All participants†	Less than 1 day a week	215	76.2
		One day a week or more	67	23.8
Living with a current smoker	All participants†	Yes	49	17.4
		No	233	82.6
Age of smoking initiation	Current and former smokers*	12–17	105	58.3
		18–24	65	36.1
		25–33	10	5.6
Timing of quitting	Former smokers*	Quit before MS diagnosis	55	51.4
		Quit within year of diagnosis	15	14.0
		Quit 1 year or more after diagnosis	37	34.6
Number of quit attempts	Current smokers†	None	15	21.1
		1–5 times	40	56.3
		More than 5 times	14	19.7
		Do not remember	2	2.8
Average cigarettes per day	Current smokers*	1–5	10	13.9
		6–10	22	30.6
		11–20	31	43.1
		21–30	8	11.1
		31–40	1	1.4
Time after waking until first cigarette	Current smokers*	Less than 5 min	11	15.3
		5–30 min	36	50.0
		31–60 min	9	12.5
		After 60 min	16	22.2
Type of smoked tobacco	Current smokers*	Cigarettes only	64	88.9
		Cigarettes and other smoked tobacco	8	11.1

\*n=1 missing data  
 †n=2 missing data.  
 MS, multiple sclerosis.

12.1%). Current smokers were asked when they thought people with MS should be offered information about the benefits of quitting. Preferred times were at the time of diagnosis (n=27, 40.9%), within 1 month of diagnosis (n=16, 24.2%) and at a later time (n=15, 22.7%).

### Importance of receiving cessation support from people with knowledge about MS

Just over half of 69 current smokers expressed interest in a special programme for smokers who have MS (n=39, 56.5%) and NRT (n=35, 50.7%). Other cessation support of interest included stop-smoking medications (n=24, 34.8%), advice from their neurologist or MS nurse (n=22, 31.9%), face-to-face advice from a smoking cessation expert including counselling (n=21, 30.4%), advice from another doctor or healthcare provider (n=17, 24.6%), mobile-based programmes such as phone apps (n=16, 23.2%) and a workbook with tips and exercises (n=16, 23.2%). Less than 15% showed interest in either hospital-based service (n=8, 11.6%), web-based program (n=6, 8.7%), internet sites for quitting advice and support (n=6, 8.7%), information brochures and booklets (n=6, 8.7%), online support group (n=4, 5.8%) or telephone Quit-line service (n=1, 1.4%). Only 8.7% stated that they did not want support for quitting (n=6). Topics that at least 75% of the current and former smokers who quit after MS diagnosis thought were important for quit services to address included (in order of importance): Interactions of anti-smoking medication with MS medication (n=147, 91.3%), effect of stress due to quitting on MS relapses (n=145, 90.6%), temporary worsening of symptoms due to quitting (n=145, 90.6%), benefits of quitting on MS (n=142, 88.2%), effect on mood (n=139, 87.4%), challenges people with MS might face (137, 85.1%), side effects of anti-smoking medication (n=136, 84.5%), withdrawal symptoms of quitting smoking (n=136, 84.5%), benefits of quitting on general health (n=130, 80.7%), effect on relationships (n=124, 77.0%) and weight gain (n=123, 76.4%).

### DISCUSSION

Our sample was similar to the Australian MS Longitudinal Study (AMSLS) cohort,<sup>24–26</sup> which has been validated as representative of the Australian MS population,<sup>27</sup> when comparing demographic variables including education level, state of residence, remoteness, employment status, MS subtype and level of disability. However, it is possible that younger people, women and people with lower disease duration are over-represented in our sample (AMSLS women 77.7%<sup>27</sup> versus present sample 88.0%; AMSLS mean age (SD) 55.7 (11.2) versus present sample 46.7 (12.1); AMSLS mean disease duration (SD) 16.1 (11.2) versus present sample 10.4 (9.9)). Smoking prevalence is higher in our sample of Australian adults with MS (25.7% were current smokers, of which 23.6% daily smokers, and 38.0% former smokers in our sample) compared with the 2019 national average estimates for adults at 11.6% daily smokers and 24.3% former smokers.<sup>28</sup> Current smokers in our study were commonly long-time heavy smokers who had attempted to quit in the past. More than a quarter of the current smokers (28.2%) had attempted to quit in the previous year (similar to 31% in the general population<sup>28</sup>) and the majority considered quitting in the next

**Table 4** Short-term changes in symptoms or well-being immediately after smoking

Symptoms	Better	No change	Worse	Not applicable
	n (%)	n (%)	n (%)	n (%)
Pain	3 (4.3)	36 (51.4)	3 (4.3)	28 (40.0)
Stress	41 (58.6)	16 (22.9)	3 (4.3)	10 (14.3)
Anxiety	35 (50.0)	17 (24.3)	3 (4.3)	15 (21.4)
Depression	16 (22.9)	31 (44.3)	1 (1.4)	22 (31.4)
Fatigue/tiredness	5 (7.1)	43 (61.4)	9 (12.9)	13 (18.6)
Brain fog or alertness*	9 (13.0)	35 (50.7)	4 (5.8)	21 (30.4)
Bowel and/or bladder problems	4 (5.7)	40 (57.1)	4 (5.7)	22 (31.4)
Muscle spasms/spasticity	5 (7.1)	41 (58.6)	1 (1.4)	23 (32.9)
Sense of well-being	28 (40.0)	24 (34.3)	7 (10.0)	11 (15.7)

Current smokers only (n=70), n=3 missing.

\*n=4 missing data

6 months. Almost a quarter of all participants, including 17.1% of non-smokers, were regularly exposed to passive smoking, which may also increase the risk for poor health outcomes.

One of the top motivators for quitting was to improve MS and related symptoms, which indicated a general belief that smoking is harmful for MS. However, our results showed extremely low levels of awareness of adverse effects of smoking and passive smoking on MS onset, progression and treatment in our sample. This lack of knowledge of a modifiable risk factor represents a failing in caring for people with MS, and is consistent with other studies.<sup>12-14</sup> There is an urgent need for remedial education and action to ensure better promotion of smoking cessation as an integral part of MS care. Since information about relevant health consequences contributes to the success of cessation interventions for other groups, better education should contribute to smoking cessation success as well as avoidance of passive smoke exposure in people with MS.<sup>29</sup>

Unsurprisingly, people with MS experience many of the same motivators to continue smoking as people in the general population, including stress-relief,<sup>30</sup> which is not surprising since nicotine causes an immediate sense of relaxation.<sup>31</sup> The reported motivators to cope with stress and low mood may be more of an issue for people with MS since they experience higher levels of anxiety and depression than the general population.<sup>32-34</sup> When promoting smoking cessation, it needs to be acknowledged that many participants reported immediate benefits from smoking such as perceived well-being, which are likely major barriers to cessation attempts and success.

In the long term, however, more participants reported improved rather than worsened stress and anxiety after quitting for longer than 4 weeks. This is consistent with evidence that smoking is not an effective long-term strategy of dealing with stress and anxiety.<sup>31 35</sup> Reported improvements in sense of well-being and fatigue after quitting for longer than a month are also consistent with the literature.<sup>36</sup> Bladder and/or bowel problem was the

**Table 5** Changes in symptoms or health after quitting for longer than 4 weeks

Symptoms	Better	No change or cannot remember	Worse	Total*
	n (%)	n (%)	n (%)	n
Pain	4 (18.2)	15 (68.2)	3 (13.6)	22
Stress	11 (37.9)	13 (44.8)	5 (17.2)	29
Anxiety	10 (35.7)	13 (46.4)	5 (17.9)	28
Depression	6 (23.1)	17 (65.4)	3 (11.5)	26
Fatigue/tiredness	12 (36.4)	17 (51.5)	4 (12.1)	33
Brain fog or alertness	7 (25.0)	18 (64.3)	3 (10.7)	28
Bowel and/or bladder problems	1 (3.8)	21 (80.8)	4 (15.4)	26
Muscle spasms/spasticity	8 (28.6)	19 (67.9)	1 (3.6)	28
Sense of well-being	28 (82.4)	3 (8.8)	3 (8.8)	34

\*Only displayed to participants who had previously quit for longer than 4 weeks and reported some change in symptoms or health (n=41), instructed to only complete relevant items

**Table 6** Smoking cessation support from healthcare providers

	Current smoker		Former smoker	
	n	%	n	%
<b>Current neurologist</b>				
Never asked	7	10.4	22	22.0
Asked once, no further information	19	28.4	41	41.0
Asked several times, no further information	6	9.0	8	8.0
Asked and advised to quit, no help	34	50.7	15	15.0
Asked, advised and provided help to quit	1	1.5	2	2.0
Cannot remember	0	0.0	12	12.0
Total	67	100	100	100
<b>Other healthcare providers</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Never asked	10	14.7	16	16.2
Asked once, no advice	16	23.5	21	21.2
Asked several times, no advice	3	4.4	5	5.1
Asked (no further information)	0	0.0	23	23.2
Asked and advised to quit, no help	25	36.8	18	18.2
Asked, advised and provided help to quit	8	11.8	6	6.1
Cannot remember	6	8.8	10	10.1
Total	68	100	99	100

\*Examples provided in free text comments included general practitioner, dentist, physiotherapist, exercise physiologist, osteopath, speech therapist, psychologist, psychiatrist and occupational therapist. Help to quit could include provision of a script or referral to quit smoking service.

only symptom group for which slightly more participants reported worsening rather than improvement after quitting, although most reported no change. Overall, these results strongly indicate that there is a need to support people with MS to find less harmful ways to maintain or enhance moment-to-moment well-being.

Australian guidelines state that smoking cessation should be a key component in chronic disease management.<sup>37</sup> However, less than 30% of the current and former smokers in our study were satisfied with the cessation support that they received from their healthcare providers, consistent with our qualitative findings that the information and support needs of people with MS are often not met.<sup>14</sup> Even though most smokers reported that their neurologist had enquired about their smoking status, only half reported that their neurologist advised cessation, and only one participant reported that their neurologist provided support to quit, such as pharmacotherapy or referral to a cessation service. Further, less than one-third of the current and former smokers who quit in the past 2 years received support from a healthcare professional. The Australian guidelines for smoking cessation recommend the use of NRT or stop-smoking medications,<sup>37</sup> which generally increase cessation success by 50%–60%<sup>38</sup>; however, less than half of the current and former smokers who quit in the past 2 years used NRT and less than one-third used smoking cessation medications. These findings are consistent with those from the Australian general population, showing that people more commonly attempt to quit ‘cold turkey’, rather than

using NRT or medication, or advice from a healthcare provider.<sup>28</sup>

Our findings indicating inadequate support for smoking cessation, coupled with the poor awareness of smoking risks, indicate that critical opportunities to educate about smoking and promote cessation are missed. This gap in MS healthcare is mirrored in the management of other smoking-related diseases, such as in cancer management by oncologists in Australia.<sup>39</sup>

### Implications for practice

Health providers should be supported to follow evidence-based guidelines for promoting smoking cessation, including regularly assess smoking status, providing information and advice about the benefits of quitting on general health and MS, as well as smoking cessation support<sup>37</sup> to people with, or at risk for, MS who smoke and are interested in quitting.<sup>3 40</sup> A major focus of support should be on finding ways to help people with MS to manage their well-being without smoking; this is likely a more salient issue for them than for smokers in the general population.

Depending on the clinicians’ capabilities and resources, providing cessation support might include referrals to smoking cessation services, counselling services specialised in behaviour change, prescribing NRT and/or other smoking cessation medications, and arranging extra support with symptom management. Further, smoking cessation services likely need to improve their understanding of concerns related to



MS-specific barriers to smoking cessation, including potential management of mood disorders and other MS-related symptoms, which might temporarily worsen. Many participants were interested in a programme for people with MS who smoke, and tailored approaches to cessation support have proven helpful in other populations such as pregnant women and patients with cancer.<sup>29 41</sup> While general practitioners may be better placed to spend time providing smoking management on a regular basis, MS clinicians may also have an important role in promoting smoking cessation and communicating its importance in relation to MS.<sup>14</sup> Information provision is particularly important around the time of diagnosis, which is a time when people with MS may be most motivated to make behavioural changes,<sup>14</sup> in line with literature on the so-called ‘teachable moment’.<sup>42</sup> However, continuing support will be needed for those unable to make or sustain such a change in the stressful period following diagnosis, and to prevent smoking relapse among those initially successful.

Research is needed to understand whether collaborative efforts from the MS community (MS clinicians, patient advocates, allied health professionals) with general practitioners and smoking cessation experts increases cessation success in people with MS over time.

### Strengths and limitations

To our knowledge, this is the first survey to assess variables related to tobacco smoking in Australian people with MS. The main limitation is the potential for bias related to self-selection into the study, with those who smoke, but perhaps not those self-conscious that they smoke, and those more interested in smoking cessation more likely to participate. This could lead to an overestimation of prevalence of smoking. However, if our assumptions are correct, it might, as indicated above, underestimate lack of knowledge about the relationship between MS and smoking. Furthermore, the lack of a prespecified target sample and the inability to calculate a response rate or assess non-response bias, due to the sampling method, limit the generalisability of the study. As a result, the prevalence estimates should be treated as indicative rather than precise. We also recognise that reporting past quit attempts and healthcare professionals’ advice may be subject to recall bias, especially if these were not salient experiences. Caution should be taken in generalising to the Australian MS community, as well as other countries beyond Australia, as knowledge gaps and related concerns may be worse in countries where there is less focus on tobacco control. Researchers in other countries should replicate our study to understand local gaps in awareness and support, and preferences for cessation support. Finally, we did not collect survey data in people without MS, which could have elucidated differences in smoking cessation experiences, knowledge and barriers between people with and without MS.

### CONCLUSION

Given the greater risks of smoking for people with MS, we should be placing greater effort into promoting and supporting initiatives for successful cessation in this group. Healthcare professionals and MS community support organisations are missing crucial opportunities to promote smoking cessation, thus not meeting the needs of people with MS. MS clinicians should take every opportunity to use evidence-based cessation tools as a priority in their practice. Regular assessment, advice and quit support tailored to people with MS may help to reduce the prevalence of smoking among people with MS, which is likely to improve health outcomes.

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