

The impact of living with migraine disease in Aotearoa New Zealand

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ABSTRACT

AIM: To describe the impact of living with migraine disease in Aotearoa New Zealand.

METHODS: Online survey: Migraine in Aotearoa New Zealand Survey (MiANZ) delivered via SurveyMonkey from 22 August 2022 to 7 October 2022. Questions included: socio-demographics, the Migraine Disability Assessment Scale (MIDAS), the impact on work and open-ended questions with free text. Analysis used a mixed method approach.

RESULTS: Five hundred and thirty people from Aotearoa New Zealand (82% female; 77% NZ European/Other). Almost half of respondents had severe disability, measured by the MIDAS. Based on reported headaches days per month, 23% had chronic migraine. Significant impacts were noted on all areas of life. Themes from rich free-text data included “physical impacts”, “mental health impacts”, “impacts on work (paid/unpaid)”, “impacts on social connection” and “impacts of trying to find a cause or cure”.

CONCLUSIONS: This is the first reported survey of people with migraine in Aotearoa New Zealand and shows high levels of migraine disability. Greater awareness of the impact of migraine is needed, among the public and in workplaces, where more support and accommodation for workers with migraine could have a positive effect on productivity.

Migraine disease is a complex neurological condition diagnosed using reported symptoms and the criteria of the International Headache Society’s International Classification of Headache Disorders (ICHD) (3rd edition).¹ It is estimated to affect one in seven people globally,² and affects two to three times as many women as men.³ From the 2016 and 2019 Global Burden of Disease studies, migraine is the second highest cause of “years of life lived with disability” (YLD) worldwide, but the top cause of YLD among people aged 15–49 years old.⁴ In Aotearoa New Zealand, it is estimated that 642,000 people have migraine.⁴ Prevalence of migraine is similar for Māori, Pacific peoples and NZ Europeans (15.7%, 16.0% and 14.4% respectively).⁵

Migraine is classified as episodic or chronic, depending on attack frequency. Episodic migraine is defined as having up to 14 headache days/month. In 7–9% of people with migraine, the disease becomes chronic, where headache occurs on 15 or more days a month, for at least three months.^{6,7}

Disability from migraine can be measured using tools such as the Migraine Disability Assessment Scale (MIDAS), which uses a set of questions to assess the impact of migraine on daily life. These tools demonstrate the significant impact of migraine on nearly all aspects of life, including employment, education, household work, social

and family life, with people with chronic migraine experiencing the highest level of disability.⁸

Little research on the impact of migraine has been undertaken in Aotearoa New Zealand. From the Dunedin Multidisciplinary Health and Development Study in 1998–1999, participants at age 26 were asked about headaches in the last 12 months and 72 (7.3% of the sample) fulfilled the ICHD criteria for migraine. For 39% of these individuals, headache impaired their ability to work “quite a lot” to “very much” and 42% reported a similar high interference with social activities.⁹ No further research on the experiences of people with migraine in Aotearoa New Zealand has been published.

To address this gap, Migraine Foundation Aotearoa New Zealand (MFANZ), a charity with the mission of raising awareness of migraine disease and supporting people living with migraine in Aotearoa New Zealand, undertook an online survey in 2022: the Migraine in Aotearoa New Zealand Survey (MiANZ). The aims of this paper were to describe the impact of migraine disease on wellbeing and daily life, using data from the MiANZ survey. Our research questions were:

- How does migraine disease affect people in Aotearoa New Zealand?
- What can be done to mitigate the impact of migraine in Aotearoa New Zealand?

Methods

Study population and recruitment

Participants included anyone with migraine living in Aotearoa New Zealand. The survey was promoted through MFANZ social media and networks, including Health Navigator (now Healthify), Neurological Foundation and New Zealand Pain Society. A link to the survey was placed on the MFANZ website and media articles publicised the survey (GP Pulse, Scoop). From an initial 579 responses, four duplicates were removed. An additional 33 responses were removed as they answered <6% of the survey and did not contribute substantively to the research questions.

The final dataset included people with either a positive Migraine Identification test (ID-Migraine test™)¹⁰ (n=513) or who reported being diagnosed with migraine by a health professional (n=17). A positive ID-Migraine test™ (answering “yes” to at least two of three questions about migraine symptoms) has a sensitivity of 84% and specificity of 76% for migraine.¹¹

Survey development, content and delivery

The survey was developed using existing questions where possible: the five question MIDAS,¹² impact on work,¹³ other long-term health conditions (including anxiety and depression) and socio-demographic questions (age, gender, ethnicity, employment status) as used by Statistics NZ and Manatū Hauora – Ministry of Health (questionnaire in Appendix). A question on number of headache days per month identified people with chronic and episodic migraine—six respondents who were unsure or didn’t know were classed as “episodic”.

The MIDAS was scored as follows: mild disability (6–10), moderate disability (11–20) and severe disability (>20). Due to an unforeseen error in the survey, question 4 of the MIDAS was omitted, meaning that the MIDAS scores will underestimate the true disability of respondents.

The survey was delivered online via SurveyMonkey and piloted by six people, most of whom had migraine disease. The survey ran from 22 August 2022 through to 7 October 2022.

Ethical approval was granted by the University of Otago Human Ethics Committee (Ref: D23/156). Information about the survey was provided on the front page; hence, informed consent was inferred by participation in the online survey.

Data analysis

A mixed-methods approach to analysis was used. At the close of recruitment, survey data were exported into Microsoft Excel for cleaning, collation and analysis. Selected demographic data were re-coded (e.g., age-bands, gender, ethnicity). We prioritised ethnicity (Māori, Pacific peoples, Asian, NZ European/Other) for anyone who reported more than one ethnic group. For quantitative data, response frequencies were tabulated with number and percentages calculated where appropriate. Only descriptive statistics were used, due to the self-selecting nature of the sample.

Responses to each free-text question in the survey were initially coded separately, but with overlap between codes across questions; the second stage of coding involved creating themes across questions. Final coding formed a combined dataset of themes.¹⁴ This resulted in five themes, with sub-themes in each. Quotes to demonstrate themes are accompanied by gender, age group and ethnicity of the respondent. Respondents’ recommendations for what could be done to improve their situation were categorised into actions targeting society, workplaces and the health system.

Results

Participant characteristics

Table 1 presents the characteristics of the total survey sample and for those with chronic and episodic migraine. The majority were women (82%) and NZ European/Other (77%). Most were in either part-time or full-time employment (70%), with a small number of retirees and students. Almost half of the respondents met the criteria for severe disability.

Survey quantitative results

Although the majority (51.9%) of respondents had 7 days or less of headache a month, nearly a quarter of respondents (22.6%) had chronic migraine, experiencing headache on 15 or more days a month. Of those with chronic migraine, 20% had continuous or nearly continuous headache (4.5% of all respondents) and another 22% had 24 or more days of headache per month (4.9% of all respondents).

Respondents were asked questions (as per the MIDAS) about how often migraine impacted their everyday life. Figure 1 shows that half of respondents hadn’t been able to do household work, nearly a third had missed family, social or leisure activities

Table 1: Socio-demographic characteristics of the survey sample by episodic and chronic migraine type.

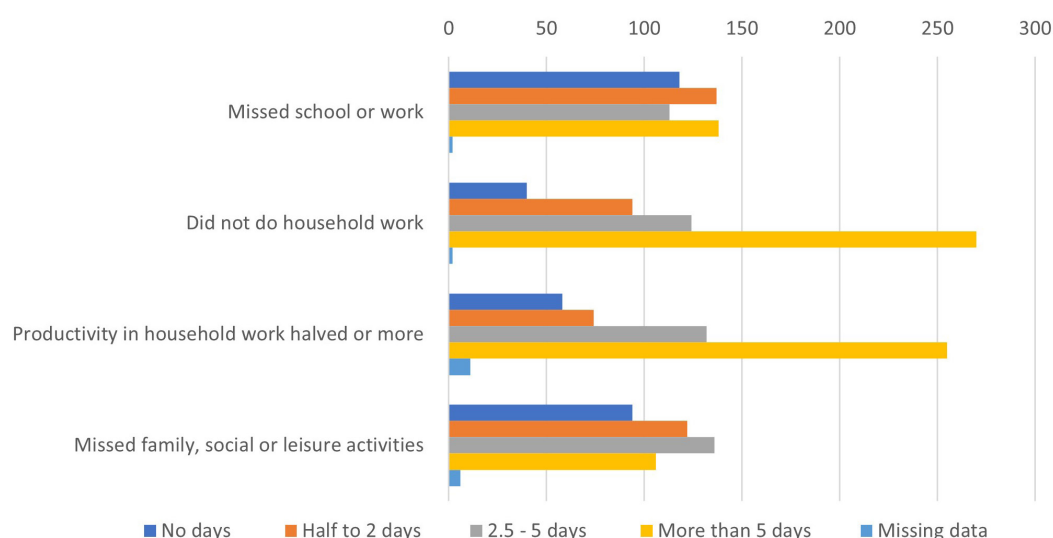
Characteristic	Migraine type					
	Chronic n=118 (22.2%)		Episodic n=412 (77.7%)		Total n=530	
Age-band	N	Col %	N	Col %	N	Col %
<18 years	1	0.8	1	0.2	2	0.4
18–24 years	5	4.2	15	3.6	20	3.8
25–34 years	16	13.6	64	15.5	80	15.1
35–44 years	30	25.4	93	22.6	123	23.2
45–54 years	35	29.7	120	29.1	155	29.2
55–64 years	15	12.7	55	13.3	70	13.2
65+ years	7	5.9	24	5.8	31	5.8
Missing data	9	7.6	40	9.7	49	9.2
Gender						
Female	96	81.4	337	81.8	433	81.7
Male	10	8.5	31	7.5	41	7.7
Another gender ¹	3	2.5	5	1.2	8	1.5
Missing data	9	7.6	39	9.5	48	9.1
Ethnic group						
Māori	7	5.9	32	7.8	39	7.4
Pacific peoples	0	0.0	6	1.5	6	1.1
Asian	2	1.7	21	5.1	23	4.3
NZ European/Other	99	83.9	310	75.2	409	77.2
Missing data	10	8.5	43	10.4	53	10.0
MIDAS Disability Score						
0–5 (little or no)	1	0.8	74	18.0	75	14.2
6–10 (mild)	3	2.5	74	18.0	77	14.5
11–20 (moderate)	11	9.3	105	25.5	116	21.9
>21 (severe)	103	87.3	159	38.6	262	49.4
Self-reported mental health						
Anxiety	50	42.3	120	29.1	170	32.0
Depression	34	28.8	91	22.0	125	23.6

Table 1 (continued): Socio-demographic characteristics of the survey sample by episodic and chronic migraine type.

Employment/education						
Student	1	0.8	13	3.2	14	2.6
Stay at home carer	8	6.8	14	3.4	22	4.2
Retired	6	5.1	22	5.3	28	5.3
Not employed, not looking for work	16	13.6	18	4.4	34	6.4
Not employed/looking for work	6	5.1	4	1.0	10	1.9
Employed part-time	30	25.4	94	22.8	124	23.4
Employed full-time	42	35.6	208	50.5	250	47.2
Missing data	9	7.6	39	9.5	48	9.1

¹3/8 people who responded with “another gender” indicated their gender: Non-binary, Pansexual, Gender queer (AFAB)

Figure 1: Days of activity missed in the last 3 months because of headaches.



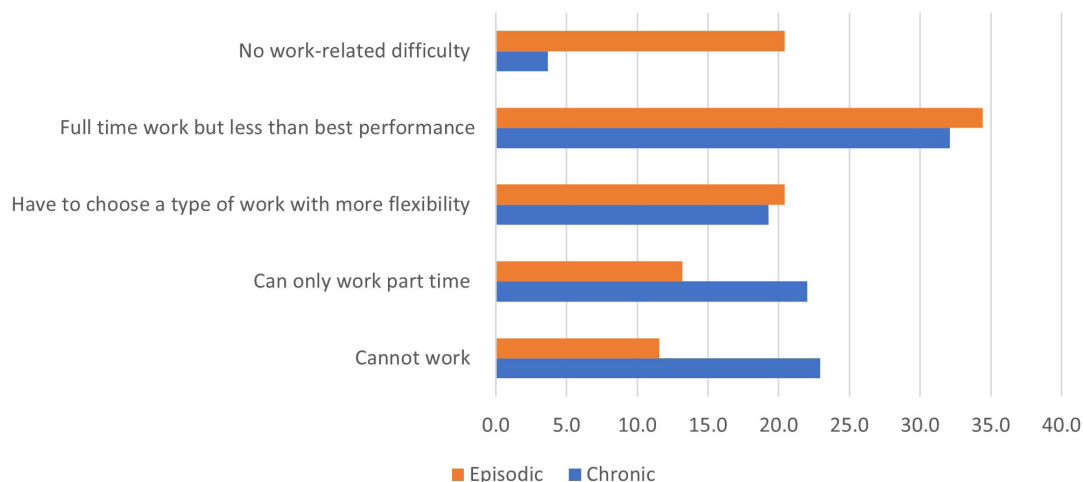
and over a quarter had missed school or work on more than five days in the last three months.

Respondents were asked to indicate the impact of migraine on work (Figure 2). Very few of those with chronic migraine reported no impact. The impact of episodic migraine on work was less, although over a third were working full-time but at less than their best performance. This is consistent with the higher rates of unemployment and lower rates of full-time employment reported by those with chronic migraine in Table 1.

Survey qualitative results

Free-text data came from three open-ended questions: “What could be done to improve your life with migraine?”, “Is there anything else you want to tell us about living with migraine in New Zealand?” and a free-text question at the end of the MIDAS. These questions were answered by 437, 254 and 67 respondents respectively.

Themes were identified under the following headings: “physical impacts”, “mental health impacts”, “impacts on work (paid/unpaid)”, “impacts on social connection” and “impacts of trying to find a cause or cure”.

Figure 2: Impact of migraine on work, proportion by episodic and chronic migraine type.

Physical impacts

Respondents spoke of significant levels of pain, which could last for hours or days. Pain was likened to no other, prompting thoughts of extreme measures to seek relief.

“People don’t understand the excruciating pain and think ‘it’s just a headache’. I’ve pondered if I could just cut my own head off to make it stop.” – 45–54 years, Female, NZ European/Other, 668

“Recently I broke my elbow. That was very painful. The migraines I experience are significantly more painful than breaking my elbow. Migraines are also significantly more disruptive to my life than not being able to use one of my arms. If I could cut off one of my arms and never experience migraines again I would do it in a heartbeat.” – 35–44 years, Male, NZ European/Other, 149

Migraine attacks include other physical symptoms, which can be as debilitating and distressing as the headache. Respondents reported loss of coherent speech, paralysis on one side of the body, auras (visual disturbance and even loss of vision), pins and needles, sensory sensitivity (photophobia, phonophobia) and nausea with or without vomiting.

“My symptoms can sometimes make me look like I’ve had a stroke because

I can’t talk or walk properly, with pain so severe I am beyond crying.” – 45–54 years, Male, NZ European/Other, 355

Mental health impacts

The effect of migraine on everyday activities could lead to anxiety and depression, with words such as “misery”, “devastating” and “ruining life” used to describe the impact. Going without a migraine attack for short periods could invoke feelings of happiness or relief.

“It sucks. It ruins my life. It changes plans, disrupts routine, creates stress. It makes me miserable.” – 25–34 years, Female, Asian, 473

Constant worry about when the next migraine attack was going to arise and how that would impact planned events could induce high levels of anxiety. Participants used combat terms such as “threat”, “attack” and “live in fear”, giving migraine disease an enemy-like persona, something to be battled against, or to be fearful of, making living with migraine possibly akin to “shell shock” or Post-traumatic stress disorder.

“I think sometimes the fear of a migraine is the worst ... I have no one to call to drive me to the doctor for an injection when I am really ill, and I end up in bed all day in extreme pain ... as a single mother it makes me feel very vulnerable.” – 45–54 years, Female, NZ European/Other, 097

Those living with chronic migraine describe only living half a life, feeling isolated, trapped, lonely and useless.

“The toll migraine headaches take on a person’s mental health is devastating and severely overlooked. You feel useless and worthless because you can’t provide.”

– 35–44 years, Female, Māori, 461

Impacts on work (paid and unpaid)

Many people noted their inability to work or study, or reduced ability to work due to migraines: “unable to work”, “I don’t work or study at the moment”, “not able to work because of them”, “I don’t work now because of my migraines”, “haven’t worked for a year, too many migraines”, “I had to quit my job 2 years ago”. As well as the obvious reasons for not being able to work (frequency of migraines and needing to lie in bed for days), the negative impact of migraine on cognition and fatigue also reduced people’s ability to function productively at work.

“Don’t work. Migraines interfere with cognitive function almost daily.” – 45–54 years, Female, NZ European/Other, 116

Those who did work spoke about being “lucky” to have flexible work schedules, reducing work hours to accommodate migraine or choosing work where regular attendance was not required. A cycle was noted of pain limiting the ability to work, trying to keep working despite impairment and then using any spare time to catch up and recover. Some people relied on acute medication to continue working.

“I have so much pain regularly and I still have to show up and drug up. I was in a senior executive job and would push through until the times I couldn’t and then I would be in bed for 3 days in the dark.” – 45–54 years, Female, NZ European/Other, 599

As well as impacting paid work, people talked about the effects on household tasks, parenting and being a responsible partner. They worried about the impact on other family members, with partners having to do extra and children being affected.

“I have had to give up my job. I can no longer drive. I don’t cook.

I often can’t bathe. I rarely do any housework. I’m dependent on my partner for everything.” – 45–54 years, Female, NZ European/Other, 963

“I can’t imagine how single parents with migraines cope!! It affects the state of one’s house. It’s just impossible to keep up with housework. It restricts your children’s lives.” – 45–54 years, Female, NZ European/Other, 116

Impacts on social connection and time

A common theme was respondents’ lack of ability to commit to social events and feeling like they were letting people down when migraine attacks kept them at home.

“I don’t tend to make plans to do things because I can hardly ever follow through.” – 25–34 years, Another gender, NZ European/Other, 759

The concept of migraine “stealing life away” was common. People talked of “lost days to migraines” and time you can never get back. The days lost to migraine attacks were also a hindrance to social contact, as good days were spent catching up on work or activities that were unable to be completed on migraine days. Avoiding triggers (lack of sleep, alcohol, places with bright lights, noise or strong smells) interfered with the ability to attend social occasions when these triggers were an integral part of socialising.

“I rarely socialise because if I don’t have a migraine, I’m catching up on all the things I’ve neglected when I’ve been experiencing one...” – 45–54 years, Female, NZ European/Other, 116

Impact of trying to find a “cause” or “cure”

People spent a significant amount of effort, time, research and money trying to find a cure, or something that would reduce the frequency or intensity of migraine attacks. They struggled with potential triggers, which could be overwhelming and often fruitless, when triggers could not be consistently identified or avoided. The time and financial investment into activities and therapies to “get better” or at least maintain a level of wellbeing could be prohibitive and restrictive.

“It’s expensive—privately funding

Table 2: Recommendations for supporting people with migraine.

Recommendations for supporting people with migraine		Supporting quote or information
Societal	More understanding, education and awareness for the general public	<p><i>“More awareness in how debilitating it is; you can’t just drink more water, rest, etc. It lasts days and it is not just the pain, though that can be very bad, [it’s] that other symptoms come with it.”</i></p> <p><i>“I feel like I live with a made-up illness, constantly having to over-explain myself and try to convince people that it’s a real condition.”</i></p>
	Recognition of migraine as a significant, complex neurological condition causing disability	<p><i>“People do not understand and think it’s just a headache. It is not seen as a serious neurological disease.”</i></p> <p><i>“If it were considered a disability, I feel like I would be treated differently.”</i></p>
	Better support for people who can’t work full-time or at all because of migraine (e.g., a benefit for people with a health condition or disability)	<p><i>“I’m unable to work, yet don’t qualify for a sickness benefit.”</i></p> <p><i>“Disability financial support (with a working partner I am ineligible for any support), as migraines are so debilitating that I feel incapable of working.”</i></p>
Workplace	Better sick and annual leave entitlements	<p><i>“Ability to have sick days when needed without guilt.”</i></p> <p><i>“Migraine leave for work. It takes a few days for me to get back to normal.”</i></p>
	Accommodation for people with migraine to manage their environment to avoid triggers.	<p><i>“Natural light in workspaces. Migraine-specific occupational health workplace assessments of computers and workstations/lighting.”</i></p> <p><i>“Working with my workplace to reduce triggers such as exhaust fumes.”</i></p>
	More understanding and awareness of migraine disease in workplaces	<p><i>“Workplaces see migraines as simply a headache and mine tends to put pressure on me to work despite my migraines being completely debilitating.”</i></p> <p><i>“Employer ... insisted I get a medical certificate any time I had one. Despite the cost and difficulty to do so while experiencing a migraine.”</i></p>
	Provide flexible work and education options	<p><i>“I work from home so that removes the biggest issue, as I can just sleep when I have a migraine and work flexibly.”</i></p> <p><i>“Having flexible teachers who understand how debilitating they are and help with setting work to catch up at home.”</i></p>
Health system	Access to more treatment options	<p><i>“Get new drugs that mean people can work ... We would rather work and pay taxes and pay back the cost of those drugs than be sick and costing via healthcare, welfare and more.”</i></p>

CGRP meds [calcitonin gene-related peptide, new medication not currently funded in New Zealand] or having to give up work ... Plus physio, psychologist, supplements.” – 45–54 years, Female, NZ European/Other, 823

“I had a decade of experimenting to find food triggers that were never identified. In the end I gave up, figuring why add misery to pain.” – 55–64 years, Male, Māori, 706

How to improve life for people with migraine

Survey respondents were asked to comment on “What could be done to improve your life with migraine?”. Responses were grouped into suggestions for what would help at a societal level, in workplaces and the health system (Table 2).

Discussion

People living with migraine in Aotearoa New Zealand reported significant levels of migraine disability and impacts on all areas of life. Impacts were particularly pronounced for people with chronic migraine who experienced higher levels of disability and more restrictions on employment. For all respondents, impacts on household chores, family, social or leisure activities and work/study were pronounced.

From the qualitative data, impact went beyond dealing with the physical pain and other symptoms associated with migraine attacks, and affected mental health, social connections and ability to work. Other impacts included the financial and time burden of researching and accessing treatments and therapists who might offer a “cure” or at least help with minimising the intensity or frequency of migraine attacks.

The themes identified in this study are similar to those found in a systematic review of psychosocial difficulties of people with migraine,¹⁵ which included general physical and mental health, pain, fatigue, emotional problems, difficulties at work, social functioning and global disability.

People with migraine commonly state that they would be better partners and parents without migraine and report a reduced ability to do household chores, missed family or social activities and negative impacts on parenting.^{16,17} Studies consistently show that migraine affects family, partners and children of people with the disease.¹⁸ These impacts were also noted by our survey

respondents.

Research from a large longitudinal survey of people with migraine in the US found that those with chronic migraine were less likely to be in paid employment than those with 3 or fewer headache days/month and who missed more hours of work per week.¹⁹ Many other studies report marked productivity impacts for people with migraine, which are worse for those with chronic migraine.^{20,21}

The impact of migraine on mental health is complex. Depression and anxiety have bidirectional relationships with migraine disease, and both are at least twice as common in people with migraine than the general population,^{22,23} consistent with our findings. Comorbid mood disorders are associated with reduced quality of life and increased disability in people with migraine and can also increase the risk of migraine becoming chronic.²⁴

However, the negative impact of migraine on mental health extends beyond comorbid mental health diagnoses. The anticipatory anxiety surrounding migraine, where people fear attacks due to their unpredictable nature, is common and can cause significant distress.²⁵ Isolation, guilt and feelings of hopelessness are other emotions described in qualitative research on the impact of migraine¹⁸ and in our population.

Searching for a cause or a cure was also noted in our analysis. People with migraine want to understand what triggers their attacks, so they can avoid triggers and reduce their attacks. However, the evolving science around migraine triggers and the migraine prodrome now suggests that many factors that have previously been considered triggers (diet, emotions, environmental factors) are much more likely to be early symptoms of an impending migraine attack.²⁶ An excessive preoccupation with potential trigger avoidance can reduce quality of life and provoke anxiety in people with migraine¹⁸ and is unlikely to be effective.²⁶

This is one of the first studies to gather data about the experience of migraine in Aotearoa New Zealand. However, this is not a representative sample of people with migraine in Aotearoa New Zealand, but a self-selected, opportunistic sample recruited largely through social media and online channels, likely not frequented by high numbers of Māori or other ethnic minorities and with more severe disease than the general migraine population (e.g., 23% of respondents had chronic migraine compared to a population rate of approximately 8%).²⁴

A broad range of actions is needed to reduce the impact of migraine disease in Aotearoa New Zealand, starting with a wider societal understanding that migraine is a complex neurological condition. Poor understanding of migraine leads to stigma and exacerbates migraine-related disability.²⁷

For people with migraine who are unable to work at their full capacity, more supportive work environments could help reduce work-related stress and improve productivity. For people who are unable to work at all, recognising migraine as a disability could allow more people to access benefits and contributions towards treatment costs.

Further research is needed to understand the cost-effectiveness and other implications of some

of the recommendations listed in Table 2, and to explore in detail medication use and related overuse issues.

Conclusions

Migraine is a complex, disabling neurological condition with wide-ranging physical and mental health impacts, as well as negative effects on work, social and family life. From this survey of people with migraine in Aotearoa New Zealand, levels of migraine disability were high, with the majority experiencing some limitation in work, social and family life. Greater support and awareness of migraine as more than “just a headache” is needed, both among the public and in workplaces.

COMPETING INTERESTS

The authors have no conflicts of interest to declare. Data are not publicly available. Study participants were not asked for permission, and nor was ethical approval granted for data to be shared publicly.

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Appendix 1: Migraine in Aotearoa New Zealand survey

Migraine in Aotearoa New Zealand

Survey information

This survey is to understand the burden and impact of migraine in Aotearoa New Zealand. It includes questions about treatments you've tried, health services you've used and any issues or challenges living with migraine has on your professional and personal life.

We are seeking participants who currently live in New Zealand who have been diagnosed with migraine or have symptoms that are consistent with migraine disease. These include:

- pain on one side of the head
- pain that lasts 4 hours to 3 days if not treated
- throbbing or pulsing pain, usually moderate to severe and often worse with routine activity such as walking or climbing stairs
- sensitivity to light, sound and/or smell
- nausea and vomiting.

This survey is being run by Migraine Foundation Aotearoa New Zealand. Migraine Foundation Aotearoa New Zealand is the only registered charity in New Zealand supporting people living with migraine. Our mission is to raise awareness of the impact of migraine disease and support people living with migraine in Aotearoa New Zealand.

All responses are anonymous and remain confidential.

The survey will take around 20 minutes to complete.

Migraine identification

Do you have migraine?

These questions help identify people who have migraine disease.

1. Have you had a headache in the last 3 months?
 - Yes
 - No
 - Don't know
2. Has a headache limited your activities for a day or more in the last 3 months? (Activities includes work, study, play or other things you need to do in the day)
 - Yes
 - No
 - Don't know
3. Are you nauseated or sick to your stomach when you have a headache?
 - Yes
 - No
 - Don't know
4. Does light bother you when you have a headache?
 - Yes
 - No
 - Don't know

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

Please answer the following questions about ALL of the headaches you have had over the last 3 months. Select zero if you did not have the activity in the last 3 months.

It can be hard to remember what happened in the last 3 months, so your best guess is fine.

10. On how many days in the last 3 months did you miss work or school because of your headaches?
11. On how many days in the last 3 months did you not do household work (such as housework, home repairs and maintenance, shopping, caring for children and relatives) because of your headaches?
12. How many days in the last 3 months was your productivity in household work reduced by half or more because of your headaches? (Do not include days you counted in question 3 where you did not do household work.)
13. On how many days in the last 3 months did you miss family, social or leisure activities because of your headaches?

The total MIDAS score can be used to define four grades of migraine-related disability with grade I for “little or no disability” (0–5); grade II for “mild disability” (6–10); grade III for “moderate disability” (11–20); and grade IV for “severe disability” (≥21).

Note: one question was missed in the survey:

How many days in the last 3 months was your productivity at work or school reduced by half or more because of your headaches? (Do not include days you counted in question 1 where you missed work or school.)

Self-rated health

14. In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

Acute treatments

This section asks about what treatments you use when you get a migraine attack.

15. Do you or have you used paracetamol to treat your migraine attacks?

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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16. On how many days in the last month have you used paracetamol for a migraine attack?

0

30

17. Do you or have you used non-steroidal anti-inflammatories (NSAIDs) to treat your migraine attacks?

e.g., Aspirin, Ibuprofen (Nurofen, Brufen, Advil), diclofenac (Voltaren), naproxen (Naprosyn, Naprogesic, Noflam), celecoxib (Celebrex), meloxicam (Mobic)—including tablets that combine NSAIDs with paracetamol.

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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18. On how many days in the last month have you used NSAIDs for a migraine attack?

0 30

19. Do you or have you used sumatriptan (Imigran, Imitrex) to treat your migraine attacks?

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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20. On how many days in the last month have you used sumatriptan for a migraine attack?

0 30

21. Do you or have you used rizatriptan (Maxalt, Rizamelt) to treat your migraine attacks?

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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22. On how many days in the last month have you used rizatriptan for a migraine attack?

0 30

23. Do you or have you used opioids to treat your migraine attacks? e.g., tramadol (Tramal), codeine (including combined with paracetamol in Panadeine or ibuprofen in Nurofen Plus), Oxycodone.

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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24. On how many days in the last month have you used opioids for a migraine attack?

0 30

25. Do you or have you used anti-emetics (anti-nausea medications) to treat your migraine attacks? e.g., metoclopramide (Maxolon), ondansetron, prochlorperazine (Stemetil, Buccastem)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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26. Which of the following non-medication treatments have or do you use to treat your migraine attacks?

- Caffeine
- Occipital nerve block

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Neurostimulation device e.g., TENS machine
- Ginger e.g., tablets, tea
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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Preventive treatment

There are many medicines that can be taken to prevent migraine attacks. This section asks whether you have or would like to try preventive medicines and why you might have stopped taking them.

27. Which of the following anti-depressants have you used to prevent migraine attacks?

- Amitriptyline (Amirol)
- Nortriptyline (Norpress)
- Venlafaxine (Effexor)
- Fluoxetine (Prozac)
- Other (please specify)

Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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28. Which of the following anti-epileptic medications have you used to prevent migraine attacks?

- Topiramate (Topamax)
- Sodium valproate (Epilim)
- Gabapentin (Neurontin)
- Lamotrigine (Lamictal)
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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29. Which of the following anti-hypertensive or cardiac medications have you used to prevent migraine attacks?

- Nadolol (Corgard)
- Metoprolol (Lopressor)
- Propranolol (Inderal)
- Verapamil (Isoptin)
- Candesartan (Candesar)
- Lisinopril (Zestril)

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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30. Which of the following migraine-specific medications have you used to prevent migraine attacks?

- Pizotifen (Sandomigran)
- Erenumab (Aimovig)
- Galcanezumab (Emgality)
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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31. Which of the following hormone treatments have you used to prevent migraine attacks?

- Melatonin
- Estrogen, with or without progesterone e.g., hormone replacement therapy, combined oral contraceptive pill
- Progesterone on its own e.g., progesterone-only oral contraceptive, depot provera, progestin implant or intrauterine device/IUD
- Testosterone
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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32. Which of the following supplements have you used to prevent migraine attacks?

- Magnesium
- Riboflavin (vitamin B2)
- Coenzyme Q10
- Feverfew
- Ginger
- Butterbur
- Other (please specify)

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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33. Which of the following injections have you used to prevent migraine attacks?

- Botulinum toxin A (Botox) injections
- Occipital nerve block
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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34. Which of the following non-medication approaches have you used to prevent migraine attacks?

- Neurostimulation device e.g., TENS machine
- Meditation or mindfulness practice
- Yoga or tai chi
- Biofeedback
- Acupuncture
- Massage
- Cold therapy e.g., ice packs, cold baths
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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35. Aimovig, Emgality, Ajovy and Vyeptri are a new class of migraine prevention medication developed specifically to target migraine (calcitonin gene-related peptide or CGRP monoclonal antibodies). They have fewer side effects than most other preventive medications. Only Aimovig and Emgality are currently available in New Zealand.

If you have ever tried one of these, please tell us about your experience.

If you haven't, please tell us why you would or wouldn't try one in the future.

Healthcare use

This section asks about health professionals you have seen to help your management of migraine disease.

36. Which of the following health professionals have you seen about migraine?

- Primary care/GP
- Neurologist
- Emergency department or urgent care physician
- Osteopath

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Chiropractor
- Pain specialist
- Physiotherapist
- Nutritionist/dietitian
- Occupational therapist
- Dentist
- Pharmacist
- Acupuncturist
- Naturopath
- Massage therapist
- Optician or eye specialist
- Other (please specify)

Seen in the last 12 months	Seen in the past (>12 months ago)	Never seen—would like to	Never seen—don't want to
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37. How would you rate the knowledge of migraine and treatment options in the health professionals you have seen? (If you have seen more than one, rate the one you have seen most recently)

- Primary care/GP
- Neurologist
- Emergency department or urgent care physician
- Osteopath
- Chiropractor
- Pain specialist
- Physiotherapist
- Nutritionist/dietitian
- Occupational therapist
- Dentist
- Pharmacist
- Acupuncturist
- Naturopath
- Massage therapist
- Optician or eye specialist
- Other (please specify)

Excellent	Very good	Good	Fair	Poor	Not applicable/ haven't seen
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38. Have you ever wanted to see a health professional for migraine but were unable to?

- Yes
- No

39. Which health professional(s) were you unable to see for migraine?

40. Why were you unable to see a health professional for migraine? (multiple responses allowed)

- It was too expensive
- Waiting time to be seen was too long
- Unable to get or was declined an appointment
- Service not available where I live
- Had no transport to get there

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Difficult to take time off work
- Could not arrange childcare or care for a dependent
- Other (please specify)

41. What could be done to improve your life with migraine?

Co-morbidities

The next question is about long-term health conditions. A long-term health condition is a physical or mental illness or condition that has lasted, or is expected to last, for more than six months. The symptoms may come and go or be present all the time.

42. Which, if any, of the following long-term conditions have you been diagnosed with and currently have (in addition to migraine)? Please select all that apply

- Anxiety
- Arthritis
- Asthma
- Depression
- Epilepsy
- Fibromyalgia
- Heart disease
- Hypertension/high blood pressure
- Insomnia
- Irritable bowel syndrome
- Low back pain
- Stroke
- I do not currently have any other long-term health conditions
- Other (please specify)

Stigma

43. How often do you hide or minimise migraine symptoms for fear of being judged or misunderstood?

- Always
- Often
- Sometimes
- Rarely
- Never

44. How often do you feel judged or misunderstood because of your migraine disease by your:

- Spouse or partner
- Family
- Friends
- Workplace
- School/place of education or training
- Health professional
- Other (please specify)

Always	Often	Sometimes	Rarely	Never	Not applicable/ don't know
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Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

45. Is there anything else you want to tell us about living with migraine in New Zealand?

Demographics

The final questions are about you.

46. How old are you?

47. What is your gender?

- Male
- Female
- Another gender
Please specify

48. Which ethnic group or groups do you belong to?

- New Zealand European
- Māori
- Samoan
- Cook Island Māori
- Tongan
- Niuean
- Chinese
- Indian
- Don't know
- Refused
- Other (please specify)

49. Where do you live?

- Northland
- Auckland
- Waikato
- Bay of Plenty
- Gisborne
- Hawke's Bay
- Taranaki
- Manawatū-Whanganui
- Wellington
- Tasman
- Nelson
- Marlborough
- West Coast
- Canterbury
- Otago
- Southland
- Other (please specify)

50. What is your current employment status?

- Employed full-time
- Employed part-time
- Retired
- Student
- Stay at home carer (e.g., of children, parents)

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Not employed, looking for work
 - Not employed, not looking for work
51. What is the impact of migraine on your ability to work? (if you are not currently working, imagine trying to work with your current migraine condition)
- Cannot work
 - Can only work part time
 - Have had to choose a type of work with more flexibility
 - Full-time work but less than best performance
 - No work-related difficulties
52. In the last 12 months, what are all the ways that you yourself got income? Please do not count loans, including student loans
- Wages, salaries, commissions, bonuses etc, paid by an employer
 - Self-employment, or business you own and work in
 - Interest, dividends, rent, other investments
 - Regular payments from ACC or a private work accident insurer
 - NZ Superannuation or Veteran's Pension
 - Other superannuation, pensions, annuities (other than NZ Superannuation, Veteran's Pension or War Pension)
 - Jobseeker Support
 - Sole Parent Support
 - Supported Living Payment
 - Student allowance
 - Other government benefits, government income support payments, war pensions, or paid parental leave
 - Other sources of income
 - No source of income during that time
 - Don't know
53. What is the total income that your household got from all sources, before tax or anything was taken out of it, in the last 12 months?
- Zero income or loss
 - \$1–\$20,000
 - \$20,001–\$30,000
 - \$30,001–\$50,000
 - \$50,001–\$70,000
 - \$70,001–\$100,000
 - \$100,001 or more
 - Don't know
54. Do you have health or medical insurance?
- Yes
 - No
 - Don't know/unsure

Have more to say?

Migraine is under-recognised in every way—in funding, research, diagnosis, treatment and understanding. Telling your story about living with migraine sheds light on this disease, reduces stigma, raises awareness and helps with advocacy.

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

Question title

55. If you would like to find out more about telling your story, please leave your contact details and we will get in touch with you. These details will be kept separate from your survey responses and will not be shared beyond Migraine Foundation Aotearoa New Zealand.

Name

Email

Thanks for taking part in our survey!

We will use your responses to advocate for better treatment and support for people with migraine in New Zealand.

Please forward the survey on to other people you know with migraine who would like to contribute (this is the link: <https://www.surveymonkey.com/r/XNSTFM5>)

For more information about migraine in New Zealand, visit our website <https://www.migrainefoundation.org.nz/>

For questions or feedback about the survey, please email info@migrainefoundation.org.nz