

## 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



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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.

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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

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- 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)

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- 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)

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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 Vyepti 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

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- 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

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- 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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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)

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- 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.

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**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](mailto:info@migrainefoundation.org.nz)