Stigma & migraine disease in Aotearoa



Dr Fiona Imlach | Sarah Cahill | Suzanne Vale

migrainefoundation.org.nz

Migraine disease in NZ

- About 642,000 or 1 in 7 people in Aotearoa have migraine disease
- About 45,000 (7%) of people with migraine have chronic migraine (≥15 headache days/month)
- Migraine is the 4th largest cause of disability in NZ, similar to major depressive disorder
- There is little information on the impact of migraine in Aotearoa, particularly in Māori
- Disability from migraine can be measured using the Migraine Disability Assessment Scale (MIDAS), an internationally validated set of questions that measure the impact of migraine on daily life
- Chronic & high frequency episodic migraine are extremely disabling, affecting work, education and family & social life

100 New Zealanders



2 14 have migraine (mostly episodic, with up to 14 migraine attacks per month)



1 has chronic migraine (15 or more headache days/month, 8 with migraine symptoms)



2-3 have high frequency episodic migraine (10-14 migraine attacks per month)



What can be done?

 Greater awareness and understanding of the nature of migraine disease, especially in workplaces, schools & health care



for why

 Research (1) the prevalence & impact of migraine disease, particularly for Māori & Pacific people, and (2) the mitigating effects of access to timely, effective & appropriate treatment & support

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Stigmatising stereotypes & beliefs make it worse

- Stigmatising beliefs & stereotypes about migraine are common, especially that it's "just a headache"
- These include:
 - Gendered beliefs that migraine is a "women's disease"
 - Work-related & social beliefs that migraine is a sign of malingering or an excuse to get out of work or played-up for some other secondary gain
- These beliefs & stereotypes are common in society, including in workplaces & families, and among health professionals
- Stigmatising beliefs & stereotypes can become internalised in people with migraine, who can become reluctant to recognise or disclose their disease or seek help



Migraine's not serious - not even a real medical condition

Migraine is treatable! migraine isn't a real neurological

condition

to be a woman thing ...

to get out of H'sjust a work. headache!

Another

'migraine'

Migraine seems H's all in their Psychosomatic) head!



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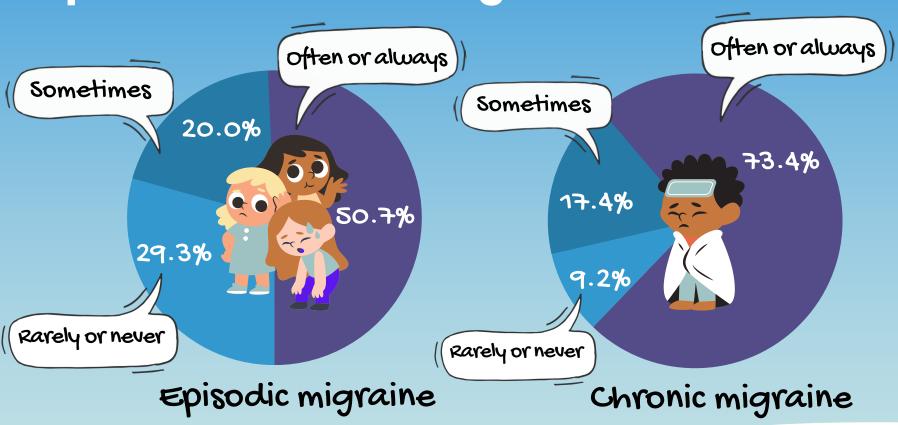
What we know: Migraine in Aotearoa NZ Survey 2022

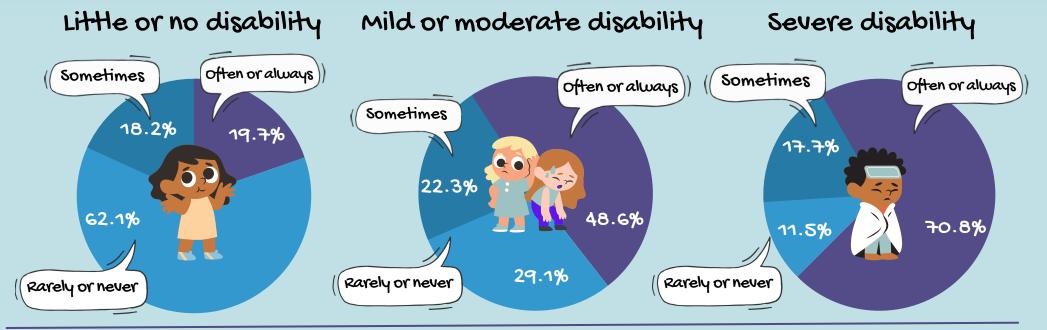
- Migraine Foundation Aotearoa NZ did an online survey of people with migraine Aug-Oct '22, recruited through social media, community and other stakeholder networks
- Of 530 respondents, 484 answered questions about stigma*
 - 56% reported always or often hiding or minimising migraine symptoms for fear of being judged or misunderstood
 - This was significantly higher in people with chronic migraine
 & people with severe disability from migraine
- These statistics indicate high levels of perceived and internalised stigma

We asked:

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

People with more disabling migraine experienced more stigma:







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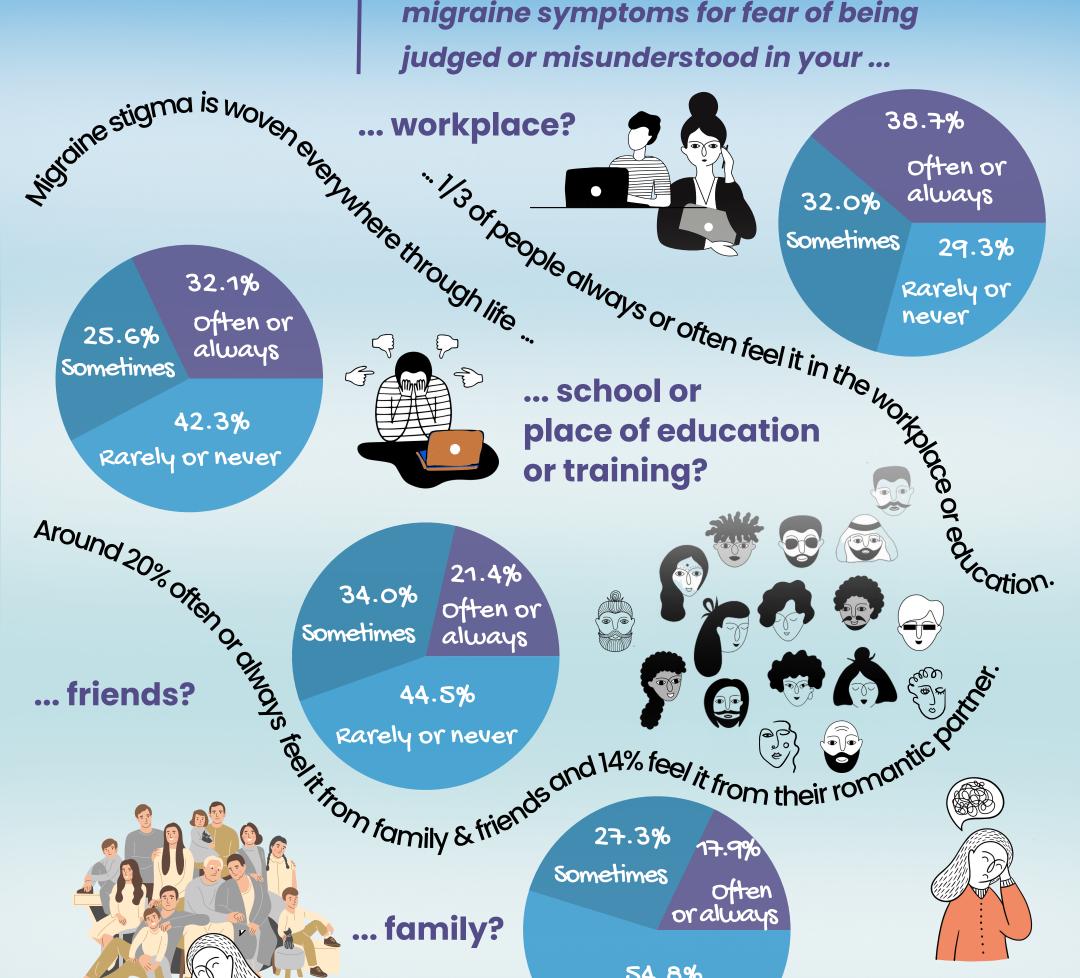
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Experiences of migraine stigma

We asked:

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



54.8%

Que sometimes feel it from health professionals.

20.3% Sometimes 13.6% Often oralways 66.0% Rarely or never

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These are big reasons to increase awareness, understanding & research