

Community Advocacy Toolkit

Migraine and Headache Awareness Week



July 2023

CONTENTS

| | |
|---|---|
| SCHEDULING A MEETING WITH YOUR LOCAL MP AND SENATOR | 3 |
| PREPARING FOR YOUR MEETING | 4 |
| FOLLOWING YOUR MEETING | 5 |
| FAQ | 5 |
| GENERAL TIPS AND POINTERS | 6 |
| MIGRAINE IN AUSTRALIA | 6 |
| MIGRAINE IN THE WORKPLACE | 6 |
| MEETING REQUEST LETTER | 7 |

YOUR ADVOCACY CHECKLIST

Use the following checklist to help organise and plan your meeting with your MP.

| Timing | Activity | Completed (tick) |
|------------------------|--|---------------------|
| Before meeting with MP | Write down the 3-5 things you want to tell your MP about your story and the 1-2 things you want to ask them to do after your meeting | |
| During meeting with MP | Tell your MP your story | |
| | Explain why it's important for parliamentarians to support people living with migraine and have 1-2 clear asks | |
| After meeting with MP | Send a thank you note | |
| | Share how your meeting went with Migraine & Headache Australia | |
| | Follow your MP on social media | |
| | Keep in touch with Migraine & Headache Australia to hear firsthand on the activities they are organising and how you can bring them to your MP's attention | |

WHAT WE'RE ASKING FOR

Migraine & Headache Australia are calling on the Federal Government to support the:

- Implementation of a proven workplace productivity program to reduce the burden of migraine in the workplace and lower the economic impact caused by migraine related productivity loss, with a particular focus on women.
- A national awareness campaign aimed specifically at women, who face the greatest burden of disease, engaging the community, primary care and the workplace.

SCHEDULING A MEETING WITH YOUR LOCAL MP AND SENATOR

How to identify and contact your local MP and Senator

1. You can identify your federal electorate by entering your postcode at <https://electorate.aec.gov.au/>
2. Visit the Parliament of Australia website and locate your electorate MP and state Senators, and their contact information here: https://www.aph.gov.au/Senators_and_Members/Guidelines_for_Contacting_Senators_and_Members

Why is meeting with your local MP and Senator so valuable?

Your local MP and Senator are regular Australians just like you. They are often former police officers, lawyers, businessmen or nurses who are passionate about advocating and acting on behalf of their constituents. As someone living with migraine, sharing your lived experience with your local MP and Senator will help them understand the issues that matter to you, and change their perspective of the disease from a statistic to a person who requires their support and voice in parliament.

With migraine advocates, like yourself, from across the country doing the same with their local MPs and Senators, we are building a movement of political supporters who will champion migraine in government.

Our aim is to address the burden of migraine that is disproportionately experienced by women through increasing awareness, reducing stigma, improving rapid diagnosis and ensuring supportive workplaces to reduce impacts on the economy and productivity.

How to secure a meeting with your local MP and Senator

1. Draft a letter to your MP and Senator requesting to meet

Below is a template meeting request letter you can use as a guide to connect with your local MP and Senator. This letter is an opportunity to begin telling your lived experience, inform

your MP/Senator of the issues that you would like their support on and invite them to meet with you in their electorate office.

When sending your meeting request letter, be sure to include contact information (mobile number/ email address etc.) to ensure their office can contact you.

2. Email your meeting request letter to your MP and Senator

Migraine & Headache Australia will provide you with your local MP and Senators' contact information (email address and electorate office phone number).

When you are ready to send your meeting request letter please do so via email. They receive a lot of emails every day and it is unlikely that you will get a response straight away – this is normal.

3. Call your MP's electorate office/ your Senators office to confirm they have received the meeting request

If you have not received a response from your local MP or Senator's office a week after sending your meeting request letter, we recommend you call their electorate office and follow up.

The diary manager in the electorate office is responsible for any meeting requests received and will have the ability to search for your letter and can put it to the top of the pile.

4. Confirm your meeting

The diary manager will reach out to you via email or by phone to confirm your meeting.

PREPARING FOR YOUR MEETING

Your lived experience is a powerful way to connect with your local MP and Senator. It might be helpful to think about the five key points that you would like them to know about your lived experience. This may include:

- When you first experienced a migraine attack and what it was like.
- How living with migraine has impacted you physically and mentally.
- The impact migraine has had on your ability to work, and any experiences you may have had of discrimination.
- Why it is important to you that your local MP advocates on behalf of you and all those living with migraine.

What does change look like for you?

Your local MP and Senator will likely be engaged with your lived experience and want to help. It is important to consider having a response to the question 'what would you like me to do?'

Migraine & Headache Australia has identified priorities that government can act upon. In speaking with your local MP or Senator it will be beneficial to weave in the #MigraineMatters messaging.

If your MP and Senator wants to help advocate for change, you can ask them to:

- Write a letter to the Minister for Health and/or Prime Minister;
- Advocate to their colleagues;
- Make a speech to the Parliament;
- Ask questions within the Parliament;
- Promote migraine awareness materials on social media

FOLLOWING YOUR MEETING

In the days following your meeting, send a thank you note to your MP and Senator for their time. This can be an email or a handwritten card for a more personal touch. We have included a template thank you letter in this toolkit that you can edit if you wish.

FAQ

What do I need to know about my MP and Senator?

Your MP and Senator website and social media channels are also a great way to see what they have been talking about recently.

What if I need to reschedule the meeting?

If you need to reschedule the meeting, speak with their office early and find a new meeting time that suits you both.

What do I do if my MP or Senator doesn't want to meet with me?

MPs and Senators have busy diaries full of local community events, meetings with constituents like yourself, as well as parliamentary responsibilities. If your local MP or Senator is a Minister or Shadow Minister, then they can spend weeks at a time on the road developing policies or speaking with various groups within the sector.

If you do have trouble with meeting with your MP or Senator, reach out to Migraine & Headache Australia and we can work through it with the office directly. Often, it's an issue of timing.

How do I stay in contact with my local MP or Senator?

Follow them on their social media handles e.g. Facebook, Twitter, or sign up to their newsletter. They may also signal during the meeting other ways that you can stay in contact as they may want to continue to hear about your experience living with migraine.

GENERAL TIPS AND POINTERS

- Be prepared and more importantly, be yourself.
- Remember, MPs are just people.
- MPs love to hear stories – don't feel like you must stick to the facts.
- Be ready for an MP to ask if they can share your story with their colleagues, with decision makers, and within the parliament.
- Don't be afraid to ask them for advice!
- All Members of Parliament are important – creating relationships with MPs, not just your local member will continue to drive awareness to decision makers.

MIGRAINE IN AUSTRALIA

- Women are disproportionately affected by migraine, making up nearly three thirds (72%) of migraine sufferers.
- Despite affecting such a large proportion of the population, women who suffer from migraine experience stigma associated with their condition, as society commonly perceives migraine as 'just a headache'.
- Because of this, almost half of migraine sufferers hide their condition from others such as their employer and their family.

MIGRAINE IN THE WORKPLACE

- Despite 4.9 million Australians living with migraine, it remains widely misunderstood and highly stigmatised, particularly in the workplace.
- Only 13% of Australians know that migraine is a neurological condition – the majority (64%) define migraine as a bad headache with additional symptoms, with 20% believing it is just a headache, or a bad headache.

- Almost 1 in 4 (23%) of Australians believe that people use migraine attacks as an excuse to get out of work or school.
- Workplaces commonly downplay the seriousness of migraine, with sufferers reporting that only 12% of Australian workplaces treat migraine as a serious condition.
- More than 1 in 4 (26%) of women living with migraine have experienced discrimination in the workplace due to their condition.
- Almost 1 in 4 (23%) of Australian women living with migraine have chosen to leave a workplace due to a lack of support for their condition, rising to 38% for frequent migraine sufferers.
- Almost 1 in 4 (23%) have considered leaving the workforce entirely due to their debilitating migraine attacks.
- 1 in 5 report that migraine has had a profound impact on their career progression – for frequent migraine sufferers, this figure increases to more than 1 in 2 (54%).

MEETING REQUEST LETTER

We have developed a template meeting request letter for you to e-mail or send to your local MP and/or Senator. Feel free to amend the body of the email to suit your lived experience.

[INSERT DATE] 2023

Senator [The Hon/Mr/Ms] [FIRST NAME] [LAST NAME] MP

[The Hon/Mr/Ms] [FIRST NAME] [LAST NAME] MP

[INSERT MINISTRY POSITION, if relevant e.g. Minister for Health]

Member for [INSERT ELECTORATE]

[INSERT ELECTORATE OFFICE ADDRESS]

Dear [The Hon/Mr/Ms/Mrs] [INSERT LAST NAME],

My name is [INSERT FULL NAME], I live in [insert town/suburb/community] and [I live with chronic migraine/ frequent migraine attacks/debilitating migraine attacks].

Despite 4.9 million Australians living with migraine¹, it remains widely misunderstood and highly stigmatised. Migraine is more than just a headache – it is a serious neurological condition that disproportionately affects women, who make up nearly three quarters (72%) of migraine sufferers.

Migraine presents a major barrier to women's participation in the workforce, with a staggering 86% of women with migraine aged between 20 and 45. Sadly, women who suffer from migraine are often overlooked for career advancement opportunities because of absenteeism or the misconception that they cannot handle their duties.

A recent survey commissioned by Migraine & Headache Australia found that almost 1 in 4 (23%) of Australian women living with migraine have left a workplace due to a lack of support for their

condition. For frequent migraine sufferers (those who experience migraine 11 days or more per month, this number is 38%.

[INSERT DETAILS OF YOUR LIVED EXPERIENCE]

I hope you can find the time to meet with me and discuss my lived experience, as well as understand what more we could do. I can be contacted directly via phone [INSERT PHONE NUMBER] or email [INSERT EMAIL ADDRESS].

Many thanks for considering this request.

I look forward to hearing from you.

Yours sincerely,
[INSERT NAME]

1. Migraine in Australia Whitepaper, Deloitte Access Economics Report, 2018
2. PureProfile Survey, June 2023.

THANK YOU LETTER

We have developed a template thank you letter for you to e-mail or send your local MP following your meeting with them. Again, feel free to tailor the body of the email to suit your lived experience and your own way of writing.

[INSERT DATE] 2023

Senator [The Hon/Mr/Ms] [FIRST NAME] [LAST NAME]
[The Hon/Mr/Ms] [FIRST NAME] [LAST NAME] MP
[INSERT MINISTRY POSITION, if relevant e.g. Minister for Health]
Member for [INSERT ELECTORATE]
[INSERT ELECTORATE OFFICE ADDRESS]

Dear [The Hon/Mr/Ms] [INSERT LAST NAME],

Thank you for your time and the opportunity to meet last week to discuss migraine and the support needed to ensure Australians impacted by this disease receive the best treatment and care possible.

As discussed, Migraine & Headache Australia are focusing on the impact of migraine on women's health and wellbeing. During Migraine & Headache Awareness week this year, they are calling on the Federal Government to:

- Implement a proven workplace productivity program to reduce the burden of migraine in the workplace and lower the economic impact caused by migraine related productivity loss, with a particular focus on women.
- Support a national awareness campaign aimed specifically at women, who face the greatest burden of disease, engaging the community, primary care and the workplace.



Again, I would like to thank you for taking the time to listen to my lived experience and hearing the action that must be taken. Your support and voice in Parliament on this issue is very much appreciated.

I look forward to connecting again soon to discuss progress.

Please do reach out if you have any additional questions.

Yours sincerely,
[INSERT NAME]