



Migraine Australia

Pre-Budget Submission 2020-2021





4.9 million Australians live with migraine



1 in 3 adult women live with migraine (71% of migraine patients are women)



Migraine costs the Australian economy \$36b per year



Migraine Australia is the only patient organisation in Australia for people living with migraine

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Cover: photos of people living with migraine sent in to our 151 Faces of Migraine campaign launched in Migraine Awareness Month 2020.

Read the stories at www.151faces.migraineaustralia.org

Foreward

Migraine is a genetic, incurable, serious neurological condition that affects an estimated 4.9 million Australians¹.

Many people with migraine will live relatively unencumbered lives and are able to manage their infrequent attacks. But migraine is a spiralling condition, and at some point, those who dismiss their migraine as 'just a headache' will find their attacks becoming more frequent and more severe. And the more they try to drown them with painkillers, or will them away by ignoring them, the more frequent and severe those migraine attacks become, until they are completely debilitated.

Migraine disproportionately affects working age women², and as a result has a significant impact on the economy, business, and significantly contributes to the gender pay gap. It has a huge impact on families, with many anecdotes of children being forced to care for their mum, or taught how to call an ambulance for their mum at a very young age, as well as evidence of higher rates of domestic violence and family breakdown.

But migraine can be managed. The most effective way to manage it is 'hard and fast': getting on top of attacks quickly with effective medication, developing healthy routines and diets uniquely tailored for each patient, and having appropriate and effective preventative medication ready to deploy once the frequency of attacks is above a level that can be managed acutely.

To do that, however, a patient first needs to be aware and informed about their condition: most are not. They need to work with medical professionals who understand the complexity and severity of migraine: most do not. And they need their employers, Government, and the community at large to understand and respect their condition, recognising it as a disability and not some failure of their own behaviour, weakness of character, or 'just a headache'. This does not happen at the moment.

Migraine Australia is the only patient body for people living with migraine. We are run by patients, for patients, and all of our people are volunteers. We do not intend to change this in the short term as we have many things that need to be done, and we want to keep every cent in the field, making a difference, rather than paying overheads. This is a particularly challenging time to be a new charity, without any established donor base, but we are confident that if we continue to be thrifty and make smart use of our people, that we can make a significant difference with just a little help.

The proposals outlined in this pre-budget submission are similarly thrifty, designed to maximise our large volunteer workforce, and make the greatest possible change in the fastest possible time, while being respectful of the unprecedented pressure the COVID-19 pandemic has created on the budget. They include conducting some basic, cornerstone research on migraine in



Raphaella Kathryn Crosby Chair,
Migraine Australia

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Australia; training for volunteer migraine ambassadors who will work in their local communities to support patients and clinicians while also raising awareness of migraine; developing resources for clinicians; and partial support for conducting our major national awareness event Migraine Awareness Month.

We are realistic and pragmatic in understanding the task at hand: turning the giant ship of migraine management and stigma around is no small task and needs to be done in stages over many years. We are in the very first stage. All we are trying to do at the moment is raise general awareness of migraine amongst those who live with it and the medical community, and bring the migraine community together so we can support each other.

There are things we know we need, for example, a national strategy for the management of migraine and individual migraine management care plans. However, we feel that we need to bring the discussion about migraine to a more mature space before the development of a national strategy or other reform efforts will be effective. The proposals we present here are our attempt to bring about that maturity, and to try and avert some of the more urgent problems people living with migraine are experiencing.

These modest proposals will help us to support more people living with migraine, improving both the health and welfare, and address the two most significant areas of need we have identified: lack of understanding of migraine, and, lack of basic research about migraine.

Outside of these specific proposals, we know we need a lot more academic research into migraine, including on the social and economic impact of migraine in Australia. We feel an NHMRC targeted call for research would be appropriate, as well as a parliamentary inquiry into migraine so we can get the facts on the table and understand the extent of the problem. And, as we have raised with the Government previously, we need the new migraine treatments recommended for the PBS to be listed urgently. These things have not been itemised in this proposal as none of these would involve funding direct to Migraine Australia, but we note them so there can be no doubt of our support for these desperately needed elements in improving the way we manage migraine.

Migraine Australia has already achieved much in our young life. We need to do more urgently. Taking action on this much neglected disorder will have immediate and substantial benefits for the broader community and economy, as well as transforming the currently miserable experience of those living with significant migraine.



Raphaella Kathryn Crosby Chair,
Migraine Australia

Priority Objective	Proposal	Cost
Priority Objective 1: Provide cornerstone data on migraine in Australia	Proposal 1: Migraine Prevalence and Awareness survey	\$93,000
	Proposal 2: Surveys of the migraine community	\$2,880
Priority Objective 2: Support & empower patients through awareness and promotion.	Proposal 3: Support and develop Migraine Australia Ambassador program	\$120,000
	Proposal 4: Implement local support groups across Australia	\$7,700
Priority Objective 3: Increase the understanding of migraine within the community.	Proposal 5: Develop and distribute materials to increase awareness and support GPs and other clinicians in managing migraine patients.	\$135,000
	Proposal 6: Migraine Awareness Month 2021	\$25,000
Total:		\$383,580

Priority Objective 1: Provide cornerstone data on migraine in Australia

Possibly the most significant barrier to improving the management of migraine in Australia and effectively supporting people who live with migraine and their families is the astounding lack of data on migraine in Australia.

There is no basic prevalence data to tell us how many people live with migraine. We do not know when and how people are getting diagnosed, what their comorbidities are, or what impact migraine is having on their lives.

Additionally, the Australian Institute of Health and Welfare has never done a report on migraine. World Health Organisation reports on migraine state that no data is available for Australia.

In 2018, Deloitte Access Economics produced a white paper for the pharmaceutical company Novartis on Migraine in Australia. These numbers are useful but are based on US prevalence information so may be significantly off the mark. Government, health care providers, and Migraine Australia as the only organisation supporting migraine patients, desperately need reliable numbers on migraine in Australia.

Proposal 1: Migraine Prevalence and Awareness survey

We propose to resolve the lack of data problem in the short term by conducting an online survey through a commercial polling provider. This would be a basic prevalence and awareness survey of adults; incorporating questions from the Migraine Literacy survey developed by Stephanie Goodhew at Australian National University which measures the awareness of the condition and treatment options.

By doing this survey through a commercial polling firm, we can generate the desperately needed numbers quickly and relatively affordably, and with a much larger sample. The intended study will survey approximately 15,000 people to give a high accuracy rate and low margin of error than most surveys. The turn around time will also be much faster than an academic study, enabling us, others in the sector, and Government to get to work on planning and developing strategies for better management of migraine in a matter of weeks. It is not a substitute for an academic study of

prevalence, as it will be limited to people over 18 and thus pediatric prevalence will not be captured, however as migraine attacks are more common in working age people it will give us very solid information to work from. National prevalence and awareness data must be collected nationally and from a very large sample, and it is beyond the capacity of our volunteers to do this cornerstone work.

Proposal 2: Surveys of the migraine community

Using the cornerstone figures, our volunteer team of researchers will then conduct a series of further surveys into:

- quality of life;
- quality of medical care;
- use and effectiveness of migraine treatments;
- impact on work performance and ability to stay in work;
- need for welfare and disability supports;
- impact on families, including domestic violence and marital breakdown;
- the financial cost of migraine on individuals and their households; and
- further study into stigma of migraine.

We can undertake these additional studies using our volunteer team of researchers (mostly current PhD students or employed in academic research) at minimal cost, but we cannot do them effectively without the cornerstone prevalence and awareness data, and appropriate survey software.

Proposal	Detail	Cost
Proposal 1: Migraine Prevalence and Awareness survey	Conduct large survey through a commercial provider	\$93,000
Proposal 2: Surveys of the migraine community	Licence for survey software	\$2,880
Total:		\$95,880

Priority Objective 2: Support & empower patients through awareness and promotion.

Awareness of migraine is very low, even among those who live with the condition. It is estimated that 50% of people living with migraine have never spoken to a doctor about their symptoms, and most who have been diagnosed have very low awareness of how to manage and treat their condition. Additionally, there are no support services available other than our social media channels and Facebook groups.

Proposal 3: Implement the Migraine Australia Ambassador program

We will be introducing a migraine ambassador program, recruiting 150 volunteers to cover 50 regions across the country. These ambassadors will perform three essential tasks:

- Be instrumental in raising awareness in their area through establishing relationships with local doctors and other support services who can connect people living with migraine with Migraine Australia.
- Host local support groups of people living with migraine.
- Raise awareness online and through their local media.

To enable this program to be successful, we propose to train our ambassadors in migraine literacy, legal

Proposal	Detail	Cost
Proposal 3: Implement the Migraine Australia Ambassador program	Ambassador training	\$120,000
Proposal 4: Implement local support groups across Australia	Support group management system	\$4,200
	Resources for support groups	\$3,500
Total:		\$127,700

issues in the provision of support and management of health information, and effective use of media. This will enable our army of ambassadors to confidently engage in the urgent and important work of raising migraine awareness, supporting others living with migraine, and empowering them and those they connect with to better manage their migraine.

Proposal 4: Implement local migraine support groups across Australia

Support has been identified by our members as one of their greatest areas of need. Providing support for millions of people nationwide is an enormous challenge, but one we believe we can do by utilising our greatest asset: our passionate volunteers.

Our Ambassadors will be asked to host local support groups and bring together their local migraine community. These local groups will be varied and unique to each community: some will prefer to meet in a café, others in someone’s home, while some may opt for neutral community venues, or may work with local health services to hold gatherings on site.

We estimate that there will be at least 12 local support groups formed for each region (one per week for each ambassador), each supporting an average of 25 people living with migraine, providing direct and in-person support to more than 15,000 people living with migraine within the first year. If proven successful, we would seek to add to the program with more support groups, and a qualified social worker to coordinate the program and provide a higher level of mental health and welfare support to Ambassadors to help them manage people in significant distress.

A small budget for an effective management system for the support groups, materials, signage and advertising of events will ensure the rapid establishment of this network of volunteer run support groups and consistency in the support experience.

Priority Objective 3: Increase the understanding of migraine within the community.

The stigma of migraine is pervasive and entrenched. A recent survey of Migraine Australia members found that only 6% of people living with migraine do not feel affected by the 'just a headache' myth and other stigma of migraine. Surprisingly, medical professionals were revealed as the most significant source of stigma³.

The very broad lack of understanding of what migraine is and how it can effect people is not something that will be fixed easily or quickly. This priority is to start working on the stigma problem with the two groups that matter most: the doctors who treat us, and the people who live with migraine, particularly those with low severity or infrequent migraine attacks who may have never seen a doctor, or do not understand the very basics of their condition.

Proposal 5: Develop and distribute materials to support GPs and other clinicians in managing migraine patients.

Information around migraine; specifically migraine management, is scarce. There are limited readily available resources which prevent patients and their careers understanding the complexity of migraine. GP's, specialists and other allied professionals, including physiotherapists and psychologists, have asked us to provide them with material that they can give to patients and their carers.

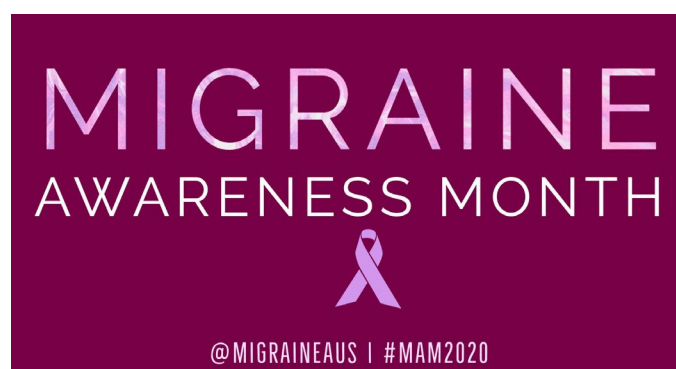
This will include:

Development of migraine fact sheets, including the different sub-types of migraine and effective strategies for migraine management, which clinicians or patients can download from our website.

Working with other patient bodies for conditions that are more common in people with migraine, such as allergies, endometriosis, stroke and heart disease,

develop fact sheets on how the two conditions affect each other, information that is generally not currently available, and make them available to download from both Migraine Australia's website and our fellow organisations.

Distribution of small migraine pamphlets to GP's, specialists, and other allied professionals, including physiotherapists and psychologists around the country for them to give to patients or have available in waiting rooms.



Proposal 6: Migraine Awareness Month 2021

Migraine Awareness Month falls in the month of June each year. There are some 40 other countries that participate in Migraine Awareness Month each year, including global campaign efforts such as Shades for Migraine, which Migraine Australia is proud to have brought to Australia in 2020. This initiative aims to bring the migraine community together, continue to empower and educate patients and their carers about migraine, and continue to raise awareness about migraine in the broader community.

Migraine Awareness Month 2020 was broken down into themes for each week, and intentionally targeted at people who live with migraine but knew very little about their condition. We provided information and resources around what is migraine, how to manage it, medication

PRIORITIES

overuse headache and wellness. We also featured interviews with doctors and researchers on the future direction of migraine care, and encouraged people living with migraine to talk publicly about what it means for them.

We achieved:

- A collection of over 300 stories of Australians who live with migraine in the #151FacesofMigraine campaign; which were shared on social media and are currently being put into an eBook. The purpose of this initiative was to put a human face to the condition, and it had the greatest impact of all our initiatives, sparking many healthy conversations among families, friends, and workplaces.
- Shades for Migraine - an international campaign asking people to take selfies with their sunglasses on in solidarity with everyone with migraine - was successfully brought to Australia, with hundreds of people sharing their photos online.
- A doubling of our social media reach with thousands of new followers.
- A number of detailed news items talking about what it is like to live with migraine, newer migraine treatments, and encouraging people with migraine to talk to their doctor about their migraine.

In 2021, in addition to similar online and media activity, Migraine Australia proposes to run local in-person Migraine Awareness Month events (COVID-19 restrictions permitting) within each state and territory to harness and build community. We will also hold a national virtual summit, and conduct a broader media campaign, utilising our Ambassadors as local spokespeople to supplement our national awareness activities. As it was in 2020, Migraine Awareness Month will be focused on the positive and empowering patients to take better care of themselves.

The requested funds would partially support this activity by enabling pre-ordering of materials, signage, and a small online advertising budget to promote Migraine Awareness Month and events such as Shades for Migraine. The remainder of the cost for this major event will be met by event tickets, sponsorships and donations.

#151FACES OF MIGRAINE



ERIC, 63
MIGRAINE
JAGAJAGA, VIC

“

I HAVE BEEN GETTING MIGRAINE ATTACKS FOR 47 YEARS SO THIS IS A LONG STORY.

”

@MIGRAINEAUS | #MAM2020

#151FACESOFMIGRAINE



JOSEPHINE, 38
CHRONIC MIGRAINE
NORTH SYDNEY, NSW

“

I HOPE THAT MY SHARING MY STORY THAT PEOPLE CAN BE MORE COMPASSIONATE AND EDUCATED ABOUT THIS DISORDER.

”

@MIGRAINEAUSI#MAM2020

Proposal	Detail	Cost
Proposal 5: Develop and distribute materials to support clinicians in managing migraine patients.	Pamphlet and factsheet development and distribution	\$135,000
Proposal 6: Migraine Awareness Month	Event materials and signage	\$10,000
	Advertising	\$15,000
Total:		\$160,000

About Migraine Australia

Migraine Australia is a national patient advocacy organisation working to support all Australians living with migraine and their families. Migraine Australia Ltd was registered as a charity with the ACNC in June 2020. We are a volunteer organisation, and all of our leadership team live with significant migraine.

We want all Australians living with migraine, whether they have a migraine attack every day, barely one a year, or anything in between, to feel supported and able to live a full and productive life. And, not feel like they have to hide their condition.

Through advocacy, information and support, and led by people living with migraine, our mission is to actively and demonstrably improve the quality of life and wellbeing of all Australians living with migraine and their families, and reduce the burden of migraine on both those directly affected and the broader community, through the prevention of migraine attacks, medication overuse headache, and other migraine related conditions.

Our goals are:

1. Advocate for people living with migraine through lobbying, making submissions, and other actions to ensure people living with migraine are heard in any decision making processes.
2. Support the migraine community by achieving practical changes that make our lives easier, improve our quality of care and life, and providing opportunities for people living with migraine to connect and share.
3. Raise awareness of migraine in Australia, from what it is, to how to manage it and how others can support people living with migraine.
4. Coordinate and encourage migraine research that benefits the health and wellbeing of people living with migraine.

Our organisation grew out of advocacy around getting the new CGRP medications for prevention of migraine attack listed on the PBS, so this will always be one of our highest objectives. But we quickly realised that migraine simply does not have the awareness, resources and support that other conditions do, and we needed to work on the much larger problem of how we manage migraine. We know, as hardened migraine warriors, that it can be managed with the right combination of medication, lifestyle adjustments, allied health treatments such as physiotherapy and psychology. However, it has taken us years of research and trial and error to get to the point where we feel like we understand this perfectly evil spectrum disorder. Our long term plan is to implement a system of migraine management plans, including support systems, that will upskill migraine patients from the point of first diagnosis so they can manage their migraine, and hopefully never have to endure the kind of debilitating migraine attacks that have stolen years of our lives.

The logo for Migraine Australia features the word "Migraine" in a large, dark purple serif font. Below it, the word "Australia" is written in a smaller, light purple sans-serif font. The two words are centered and overlap slightly.

NOT JUST A HEADACHE



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References

- 1 Deloitte Access Economics (2018). Migraine in Australia whitepaper: Measuring the Impact. Deloitte Access Economics, Sydney, <https://www2.deloitte.com/au/en/pages/economics/articles/migraine-australia-whitepaper.html>, Accessed 10/12/2018.
- 2 Rachel A. Schroeder, Jan Brandes, Dawn C. Buse, Anne Calhoun, Katharina Eikermann-Haerter, Katie Golden, Rashmi Halker, Joanna Kempner, Nasim Maleki, Maureen Moriarty, Jelena Pavlovic, Robert E. Shapiro, Amaal Starling, William B. Young, and Rebecca A. Nebel (2018). 'Sex and Gender Differences in Migraine—Evaluating Knowledge Gap's. *Journal of Women's Health*. Aug 2018.965-973.<http://doi.org/10.1089/jwh.2018.7274>. Accessed 15/7/2020
- 3 Migraine Australia (2020). Stigma survey: Migraine stigma affects 94% of people living with migraine. 25/6/2020. <http://www.migraineaustralia.org/2020/06/25/stigma-survey-migraine-stigma-affects-94-of-people-living-with-migraine/>