

Strategic Action on Chronic Migraine

Policy proposals to improve lives
and achieve budget savings

December 2019

*Submission to the 2020-21
Federal Budget from
Migraine & Headache Australia*



Migraine & Headache Australia is the only charitable organization in Australia that aims to support the more than 5 million Australians affected by migraine and headache disorders.

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FOREWORD



Trevor Thompson
Chief Executive Officer
Migraine & Headache Australia

Chronic migraine – It's more than just a headache

What is the issue?

Chronic migraine is a serious condition which has a significant impact on the health and wellbeing of many Australians, as well as a considerable impact on the Australian economy. Yet this surprisingly widespread condition has been largely overlooked in national health priorities and strategies to date.

The time has come to take action. Earlier diagnosis, treatment and migraine prevention is not only possible, but critical to improve the lives and productivity of the half a million Australians who experience chronic migraine.

The burden of chronic migraine

Migraine attacks are recognised by the World Health Organization as among the most disabling illnesses, comparable to dementia, quadriplegia and active psychosis.¹ Patients can experience severe head pain, nausea, vomiting, blurry vision or blind spots, difficulty concentrating or communicating, sinus congestion, muscle weakness and more.

Nearly 500,000 Australians experience migraine on at least eight days each month.² Over 30% are using opioids to treat their migraine attacks.¹⁵ One in three people suffering from chronic migraine also experience depression and anxiety (making them at least four times more likely than others to experience depression and anxiety).³ Patients are also far more likely to have other medical conditions that are comorbid with migraine such as allodynia (central pain sensitisation), obesity, sleep disorders, fibromyalgia, arthritis, hypertension and heart disease.⁴

Women are disproportionately affected with more severe and longer lasting migraine attacks. Approximately one in four women of working age experience migraine. Chronic migraine can drive a wedge between the sufferer and their family, friends and colleagues. It also peaks in middle age when an individual is likely to be more actively engaged in work, social and family duties.

People with chronic migraine experience considerable pain and suffering which impacts on their physical and mental health, and their workforce participation. The impact spreads even further than the half a million sufferers, to also affect their families, communities and workplaces. An estimated one in four households are affected by migraine.⁵ Children living with one or more parents with migraine are significantly affected across several domains of wellbeing. Parental migraine puts children at developmental risk with potential long-term transgenerational impacts.⁶

Where are the gaps?

Many Australians living with chronic migraine are currently unable to access best practice assessment and management of their condition due to a low awareness of treatment options and lack of access to health professionals with relevant knowledge and skills.

The Pharmaceutical Benefits Scheme (PBS) covers a significant amount of the \$1.86 billion spent each year on migraine and migraine-related prescriptions.⁹ Most prescription medications used for migraine have other primary indications which dramatically underreports the true PBS expenditure on medications for migraine.⁷

There is evidence of considerable misuse and overuse of medications used for migraine. 34% of patients with migraine use an opioid to treat the attack.¹⁵

GPs are inadequately trained and skilled in the management of chronic migraine. Just 1 in 20 patients with chronic migraine who see a doctor, receive an accurate diagnosis and appropriate treatment.⁸ This equates to a shocking 19 out of 20 patients with chronic migraine who are not seeing a doctor for their condition, or are not receiving an accurate diagnosis or appropriate treatment.

The consequences of these gaps are immense. Chronic migraine represents a significant disability which is not recognised by Australian disability services. Patients themselves are forced to simply survive with severe and debilitating pain. This strains relationships with family and friends and places more pressure on work performance. In addition, those with chronic migraine have significantly higher cost and utilization of healthcare services, with healthcare expenditure for a person with migraine averaging \$7,476 per annum.⁹

The cost of migraine extends beyond the individual and their families. In Australia, chronic migraine costs \$4.1 billion each year in lost economic output.⁹

What can be done?

This Pre-Budget Submission from Migraine & Headache Australia proposes initiatives which will make a significant difference. These include a national web-based consumer support network to reduce misuse of prescription medicines; a workplace productivity program to educate employers and return more people with migraine back to the workplace and increase productivity; initial work towards a Migraine Centre of Excellence to train GPs and provide better treatment for the highest need chronic migraine patients; an epidemiological study into migraine in Australia; and a request to increase PBS funding for the first proven effective medicinal treatment designed to prevent migraine specifically.

Better care aligns with several existing federal health priorities such as reducing harm from medications (including opioids); promoting rural health participation; managing mental health with chronic pain conditions such as chronic migraine; supporting the national pain strategy; suicide prevention and better childhood outcomes.

Addressing chronic migraine is an urgent and until now, largely overlooked national policy priority. There is a compelling case to act now. Real and immediate action will not only improve the lives of people with chronic migraine, but will benefit all Australians through economic returns, a reduction in federal health expenditure and reduced pressure on our health care system.



Trevor Thompson

Chief Executive Officer

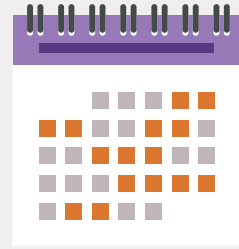
Migraine & Headache Australia

The **BURDEN** on individuals



492,000
AUSTRALIANS ARE
AFFECTED BY
MIGRAINE

on at least
15 DAYS
OR MORE
PER MONTH



IT IS AMONG THE **MOST COMMON CHRONIC**

HEALTH PROBLEMS MANAGED BY GPs



34%



of Australians
WITH MIGRAINE
USE OPIOIDS
to treat their attacks¹⁵



4.9
million
AUSTRALIANS,

1 in 4



AND AFFECTS **ONE IN FOUR** HOUSEHOLDS⁹

When **migraine is allowed to persist** without effective management, it can **progress in severity** and lead to a range of **costly comorbidities** including:



ALLODYNIA



OBESITY



DEPRESSION



ANXIETY



SLEEP DISORDERS



FIBROMYALGIA



ARTHRITIS



HYPERTENSION



HEART DISEASE

JUST
1 in 20



patients with chronic migraine **see a doctor** and receive an **accurate diagnosis** and **appropriate treatment**⁸

BURDEN on the economy and health system

FEDERAL GOVERNMENT EXPENDITURE ON HEALTH AND WELFARE SYSTEM COSTS RELATED TO CHRONIC MIGRAINE IS AN ESTIMATED

\$704 million



62.7 million workforce person/days are **lost each year** due to migraine resulting in



\$16.3 billion

in **lost productivity** each year⁹

Already there are **over 14,100 people** with chronic migraine on **disability support pensions (DSPs)**, costing over



\$300 million

in 2018¹⁰

Migraine accounts for **870,000 GP consultations** each year resulting in a



\$32.2 million

cost to the government via the Medicare Benefits Schedule (MBS)⁹

The **PBS** covers much of the **\$1.86 billion** spent each year on migraine and **migraine-related prescriptions**⁹

\$1.86 billion



MIGRAINE COSTS THE **HOSPITAL SYSTEM**

\$6.5 billion

each year⁹

Summary of proposals

Proposal 1: Improve quality use of medicines by migraine sufferers

- Most people living with chronic migraine have limited knowledge of how to effectively use medication to manage their condition, resulting in a high level of misuse and negative consequences. For example, 34% of patients use opioids to treat their migraine attacks.¹⁵
- A national web-based consumer support network to educate people with chronic migraine will significantly increase awareness, promote the effective use of medicines and provide medically reviewed resources to self-regulate medicine use.
- Investment: \$298,000 over two years.

Proposal 2: Improve the workplace productivity of people with migraine

- Chronic migraine has devastating consequences during an individual's most productive years of life (ages 33 to 55) resulting in \$4.1 billion of lost productivity each year. If workplaces were safer for those with chronic migraine more people could return to the workplace. \$30 million per annum could be saved in government expenditure if just 10% of patients were able to return to the workplace and cease reliance on disability support pensions.
- A proven migraine workplace productivity program is available to reduce the burden of migraine in the workplace with a range of educational, environmental and clinical interventions. Uptake of this program has been shown to improve understanding, improve productivity, and reduce the burden of migraine in the workplace.
- Investment: \$1.5 million over three years.

Proposal 3: Initial steps towards a Migraine Centre of Excellence to train healthcare professionals

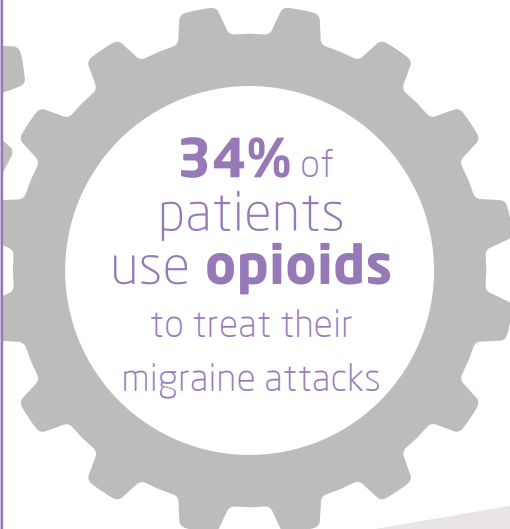
- Adequate care for migraine patients is limited at all stages of their healthcare journey by a lack of physician training, education and specialist services for patients.
- The development of a Migraine Centre of Excellence based at a university teaching hospital will train neurologists, GPs and nurses in migraine. These healthcare professionals will then disseminate their learnings and improve patient outcomes in their own clinics.
- This will improve quality of care and patient satisfaction, resulting in increased workforce participation and productivity, and reduced misuse of prescription medications such as opioids.
- Investment: \$100,000 over one year to develop a comprehensive business plan.

Proposal 4: Migraine study to prioritize focus areas and maximise impact

- To date there has been no in-depth epidemiological study to understand migraine, its burden, treatment and cost in Australia.
- To address this, funding is required for a pilot epidemiological study into migraine, to test a survey instrument as a precursor to a full epidemiological study. This will help quantify the impact of chronic migraine in Australia, identify the priorities and help translate findings into policy and practice.
- Investment: \$96,000 to fund a pilot study.

Proposal 5: Improve access to effective medications to prevent migraine

- A new generation treatment designed to prevent migraine attacks is now available in the form of Calcitonin Gene-Related Peptides (CGRP) antibodies. CGRP antibodies are a safe, effective and cost efficient treatment specifically designed to prevent migraine.
- This treatment has been recommended by the Pharmaceutical Benefits Advisory Committee (PBAC), but with unrealistic cap restrictions. Without adequate funding, most patients with chronic migraine will continue to suffer unnecessarily due to poor access to treatment. An increase in PBS funding for CGRP antibodies represents a sound investment to significantly improve quality of life, economic participation and productivity and reduce reliance on disability support pensions for those living with migraine.
- Investment: \$50 - 75 million per annum.



34% of patients use **opioids** to treat their migraine attacks

Summary of costs of proposals:

New program initiatives	
Proposal 1: Consumer support network to improve quality use of medicines	\$298,000
Proposal 2: Workplace productivity program	\$1.5 million
Proposal 3: Business plan for a Migraine Centre of Excellence	\$100,000
Proposal 4: Pilot epidemiological study into migraine	\$96,000
Total cost of new program initiatives	\$1.994 million
Proposal 5: Reform to PBS	\$50 - \$75 million per annum

Given that current Federal Government spending on migraine is calculated at \$704 million per annum²⁴, there is real potential for these proposed initiatives to result in significant budget savings.

Proposal 1:

Improve quality use of medicines by migraine sufferers



Problem: Each year, \$1.86 billion is spent on migraine and migraine-related treatments. Much of this comes from the Pharmaceutical Benefits Scheme (PBS). However, those with chronic migraine have limited knowledge of how to effectively use these medications, which leads to poorer health and higher costs.



Solution: Implement a national web-based consumer support network to inform and educate people with chronic migraine about quality use of medicines for their conditions.



Impact: Improved quality use of medicines by people with chronic migraine will reduce negative health consequences from medication misuse, such as excessive opioid usage and medication overuse, as well as reducing PBS expenditure on migraine and related medications.

Background

Approximately \$1.86 billion is spent each year on migraine treatments⁹ and misuse of these medications is common. Although the PBS covers only a few migraine-specific treatments, far higher costs are hidden behind other PBS-covered treatments that do not have a migraine-specific indication, yet are commonly used to treat migraine.⁹

Up to 80% of new patient visits to headache speciality clinics are found to misuse medications, including opioids.¹² The 'Opioid harm in Australia' 2018 report from the Australian Institute of Health and Welfare found that every day in Australia, there are nearly 150 hospitalisations and 14 presentations to emergency departments involving opioid harm, and 3 people die from drug-induced deaths involving opioid use. When migraine patients understand how opioids and other medications can worsen their condition, their usage behaviour improves. Research has shown that informed patients get better health outcomes.¹¹ The responder rate (improvement by 50% or more) for Medication Overuse

Headache (MOH) treatment is above 70%.¹² If 50% of patients with MOH reduced from chronic to episodic migraine, that would represent an annual cost saving of \$84.6 million in prescription spending alone.

Medication misuse such as excessive opioid treatments also often leads to MOH which is a headache disorder related to migraine that can result in the chronification of migraine, resistance to medication and daily symptoms. Approximately 256,000¹³ Australians are currently living with Medication Overuse Headache (MOH), yet few are correctly diagnosed and often diagnosis occurs years after onset.¹⁴ An online survey of 298 sufferers from Migraine & Headache Australia found that 34% of patients living with migraine used opioids to treat their attack. 39% of the 298 respondents had migraine on 15 days or more per month which can lead to MOH if an opioid is used for each migraine attack.¹⁵

This burden of medication misuse, opioids and migraine exacerbation is preventable. Many people are suffering unnecessarily due to a lack of access to the support and information they need to better self manage their condition.

Migraine also results in 870,000 GP consultations each year resulting in a \$32.2 million cost to the government via the Medicare Benefits Schedule (MBS).⁹ With more information and support at least 30-50% of these consultations could be saved, representing a minimum of \$10 million saving for the government.

Self-migraine management translates into wider improvements in overall health and wellbeing. Chronic migraine carries a range of significant comorbidities including depression, hypertension and heart disease. With greater self-efficacy and knowledge, patients are more likely to lead healthier lifestyles which can not only reduce the severity and incidence of migraine but also its comorbidities.

Proposal

A national web-based consumer support network will be established for people experiencing migraine. This web-based network will be evidence-based, medically reviewed and free to access. It will provide support and resources for patients to better understand and self-manage their conditions in collaboration with their healthcare providers.

The online network will update and expand upon existing information about migraine, treatment options and best practice management of prescription and over-the-counter medicines. It will also provide up to date information about where to seek help, including local healthcare networks and support groups.

A 2017 poll from Migraine & Headache Australia's community of 689 patients revealed that 30% of patients need help finding a doctor.¹⁶ We also know that 50% of people living with migraine have not yet been diagnosed.¹⁷ A self-check tool and headache doctor directory will be provided to help reduce the high level of underdiagnosis and misdiagnosis. This online diagnostic support will recommend at-risk patients to visit their GP to confirm diagnosis and appropriate treatment.

Patient case studies will also provide the migraine community examples of hope and success that they can emulate. An online support group will provide a forum of support and connection for many who feel isolated by their condition. Other tools and resources will include regular webinars with migraine experts, guides, news and events.

The American Migraine Foundation in the USA has implemented a similar initiative with a new online-based network of support for patients called "Move Against Migraine". This campaign has successfully educated more people with migraine through a dramatic increase in website traffic (now over 300,000 visits per month) and a ten-fold increase in their email subscriber base. They have also grown their online support group to over 22,000 members. This overseas initiative provides a proven roadmap to improve education and support for patients.

Approximately
\$1.86 billion
is spent each year on
migraine treatments
and misuse of these
medications is common

Up to 80%
of new patient visits
to headache speciality
clinics are found to
misuse medications,
including opioids



Cost

\$298,000 over two years.

CASE STUDY:

The **IMPACT** of **CHRONIC MIGRAINE** on the **individual**

Fiona Jeffery, Canberra, ACT



"Before migraine, I was the captain of the ACT women's ice hockey team; a member of the national women's ice hockey squad; acting

manager at work (with an interview scheduled for a promotion opportunity); studying personally for a career change; and studying for a Masters degrees through work. At home, I picked up my nephews regularly from school each week; went with my nephews to swimming lessons; commuted by bike regularly; travelled overseas each year to visit friends; travelled each year to see family interstate; shared household chores and garden work with my husband; went out with family and friends to restaurants and bars; and enjoyed live music and other stage, production and festival events. I was fiercely independent.

Migraine has changed all of that. **It has taken away my freedom, my independence, and my ability to have any sort of life outside my home.** I'm now forced to cower inside away from lights and noise and screens and all of the migraine triggers that are life itself. I am extremely sensitive to

light, particularly in summer months, and some days I have to stay inside all day with the curtains drawn and my migraine sunglasses on.

I have suffered from migraine since I was a teenager. I experienced intermittent migraines in my teens and early adult life, but since 2014, at the age of 36, migraine has become a part of my daily life. **When the migraine hits, it is the worst feeling I have ever experienced in my life.** I would do almost anything to avoid going through this. During an attack I get a sudden extreme wave of vertigo so strong that it feels like the entire world swirls around me. This is often accompanied by an anxiety attack that hits like an actual thump to the chest and rolls down my body in a wave, leaving me dripping in sweat. I can't stand. I have no point of balance, nothing stable to hold onto and nothing in my environment that is not swirling around. My eyes flicker uncontrollably from side-to-side in my head for minutes, making me extremely nauseous. If I don't get the anti-nausea medications to work and the acute medications don't work in about 5 minutes, I will start vomiting. Sometimes I don't even have a chance

to get a handle on the nausea, like when I'm woken in the middle of the night with a migraine and barely have time to grab the bucket beside the bed before I start vomiting. **I slept almost every night in 2017 with a bucket beside my bed.** When the migraine is over I'm left with the crushing fatigue and muscles that burn with lactic acid. Now I'm just tired all the time.

Initially, I used to try to cheer myself up by reminding myself that at least migraine disease is not fatal. But then I realised that if I was having chemotherapy or many other treatments for terminal illness, my life would actually be better. It would be shorter, but I would have a life where I could live instead of just trying drug after drug after drug after drug where nothing seems to work well enough to give me a life to live. I don't say this lightly. Nor do I say this with no experience of terminal illness. I say this because **migraine has completely isolated me from society.** It prevents me from accessing my work, my social activities, and almost every activity that is a basic necessity for survival in today's society. I am completely dependent upon others."

**Note: Throughout this submission we will refer to this patient to illustrate the different ways chronic migraine affects many Australians living with chronic migraine and the urgent need for these programs to support them.*

Proposal 2:

Improve the workplace productivity of people with migraine



Problem: Chronic migraine has devastating consequences during an individual's most productive years of life (ages 33 to 55) resulting in \$4.1 billion of lost productivity each year. If workplaces were safer for those with chronic migraine more people could return to the workplace. \$30 million per annum could be saved in government expenditure if just 10% of chronic migraine patients were able to return to the workplace and come off disability support pensions.



Solution: Implement a proven migraine workplace productivity program such as 'Healthy Living with Migraine' that will reduce the burden of migraine in the workplace with a range of educational, environmental and clinical interventions.



Impact: Uptake of this program has been shown to improve understanding, improve participation, productivity and reduce the burden of migraine in the workplace.

Background

Chronic migraine has devastating consequences during an individual's most productive years of life (ages 33 to 55). This imposes a heavy personal cost on the individual, their family, and their workplace. Chronic migraine results in \$4.1 billion of lost productivity each year.⁹ For each individual with chronic migraine the economic cost amounts to \$11,132 every year.⁹

Chronic migraine results in reduced employment either through disadvantages in job-seeking, for example, difficulty in searching for work or keeping a job due to frequent absences; or self-selection out of the labour force. This can lead to significant productivity losses, and to lost wages and other costs to the individual, such as reduced social engagement. A survey of 32,545 employees from nine employers found that 75% of employees with "frequent and severe" headaches have never received treatment for their condition.¹⁸

Already there are over 14,100 people with chronic migraine on disability support pensions (DSPs) in Australia costing over \$300 million in 2018.¹⁰ One in four women experience migraine attacks during their most productive and prime wage-earning years. Migraine can cause employees to be overlooked for advancement opportunities because of absenteeism or the misconception that they cannot handle more duties. As a result, those with migraine may receive lower wages, fewer promotions and fewer opportunities in the workforce.

People who live with migraine should not have to choose between quitting work or experiencing migraine attacks because of their workplace environment.

Several published studies have demonstrated the positive impact of migraine management in the workplace. One research study reviewed a program called 'Healthy Living with Migraine' with 243 employees from

a multinational financial services firm. The study found improvements in severity, workdays missed, effectiveness at work and work/activity limitations.¹⁹ Another study found that migraine work accommodations such as modified schedules, work-at-home arrangements, and special equipment have been shown to improve on-the-job performance among employees.²⁰ Using data from two separate randomized-controlled clinical trials, migraine preventive therapies were found to decrease sick days from work.²¹

If more people living with migraine are able to return to the workforce, their increasing workforce participation will result in significant increases in tax revenue and reductions in welfare payments. \$30 million per annum could be saved in government expenditure if just 10% of patients were able to cease relying on disability support pensions. This would also generate additional income tax revenue for the Federal Government.

Proposal

Migraine & Headache Australia will deliver and manage a workplace productivity program for migraine using proven protocols. It will also provide a support network and resources to help those on DSPs to return to employment.

The goal of this program is to increase participation, make workplaces safe for those with migraine and boost productivity by providing proven resources for the employer and employees. This will include an initial audit and migraine impact assessment facilitated by Migraine & Headache Australia. An educational program will help de-stigmatise migraine and provide resources for employees to confidentially seek care and find solutions to better manage their condition. Employers can also minimize migraine triggers with simple adjustments such as implementing a fragrance-free workplace policy, swapping out fluorescent lights, offering anti-glare computer screen shields and providing a quiet room.

Previous studies have mapped a clear path to engage employers and implement the program. A three-year pilot program will focus on three high incidence sectors where migraine is likely to be most prevalent. It will target financial services; teaching; and the health sector, with a focus on female nurses and doctors.

In year one, an employer steering committee with industry experts will be established to advise and guide program development. A researcher will also be recruited to design a study to evaluate the impact of our workplace program. In year two the pilot program will be refined and validated with the aim to expand with more programs within targeted industry sectors. Migraine & Headache Australia will also ensure value delivery in terms of employee productivity and health. Content licensing and paid integrations into existing employee health programs will also be sought to ensure the program's sustainability. In year three, the pay-for-service model will be refined based on industry feedback and the program expanded into other high potential sectors following the rollout model for sustainable and self-funded programs. Similar models of employer support and service payments have been developed in Australia such as the Heads Up workplace program for mental health.

75% of employees

with "frequent and severe" headaches have never received treatment for their condition

\$30 million per annum

could be saved in government expenditure



Cost: \$1.5 million over three years.

CASE STUDY:

(continued)

The **IMPACT** of **CHRONIC MIGRAINE** in the **workforce**

Fiona Jeffery, Canberra, ACT

"It's incredibly lonely being unable to work when you are only 40 years old. This is the time that everyone associates as the peak of their career years, and my friends and colleagues are all moving to different career opportunities while I cannot even walk into the building at work without getting sick.

Migraine isolates you from society. This loneliness is compounded because the very nature of the disease drives sufferers into isolation. I cannot join a support group or attend a pain clinic, and even attempting seemingly innocuous recreational activities for rehabilitation is fraught with

difficulty when they are held in a public space under artificial lighting. This often means that for weeks at a time, sometimes months when I am experiencing the worst of my illness, I often will not see anyone outside my family with the exception of medical treatment providers and one neighbourhood friend. It is incredibly lonely. And our society places such a stigma on sickness to begin with, that when you spend all this time alone with your thoughts, it is very hard not to believe that you have failed, and you have done something wrong to deserve this illness. I have experienced times of very low mood. I have often

felt very stressed and anxious about the future, particularly in light of the fact that none of the medicines appear to be doing anything to help. I worry that I will not be able to go back to work. I feel depressed thinking that this existence might be the best I can hope for, for the rest of my life. I spent practically every day in 2017 feeling so nauseated I was on the verge of throwing up and so dizzy I was often unable to walk, and at that time, I got to the point where I considered suicide. Being alive was so relentlessly distressing and uncomfortable and painful I wanted to be dead."

"I feel depressed thinking that this existence might be the best I can hope for, for the rest of my life."

Proposal 3:

Initial steps towards a Migraine Centre of Excellence to train healthcare professionals



Problem: Adequate care for those living with migraine is limited at all stages of the patient journey, due to a lack of awareness, limited clinical training and limited access to specialist services.



Solution: A Migraine Centre Of Excellence based at a university teaching hospital to train neurologists, GPs and nurses, and enable them to take this expertise back into their own healthcare centres, building a linked network of headache care.



Impact: The provision of desperately needed training for neurologists, GPs and nurses will improve patient satisfaction and quality of care. It will also increase workforce participation and productivity as well as address the misuse of prescription medications such as opioids due to more effective migraine management and a reduction in migraine-associated disability.

Background

Appropriate care for those living with chronic migraine is limited at all stages of the patient journey, by a lack of awareness, limited relevant healthcare professional training and limited access to specialist services. Freely available migraine clinics in public hospitals are at a nascent stage of development. These are generally staffed by a single neurologist trying to provide a service to the most severely affected. Australian geography adds further challenges to the provision of equitable, timely and quality care.

train
neurologists, GPs
and nurses

Proposal

This proposal is for the development of business plan to establish a Migraine Centre of Excellence. This model of chronic migraine care is based on international best practice, adapted for the Australian context. Extensive consultation will be undertaken with key Australian stakeholders to determine feasibility and integration with current chronic disease care models. The centre of excellence will support a network of GPs with an interest in migraine, and further support rural hospitals to become hubs of local migraine care.

The centralised Migraine Centre of Excellence (MCOE) (based at a university teaching hospital such as the Alfred Hospital¹ in Melbourne which has expressed interest) will comprise a group of migraine experts, migraine

nurses and allied health workers which provide support for a network of upskilled GPs (GPSIs) and rural hospital clinic hubs. The MCOE will coordinate research and clinical trial activity across the network; training for doctors (specialist neurologists and GPSI), nurses and allied health; clinical care of more complex cases; education and ongoing support of a local network of GPs with a special interest in headache (GPSIs) and rural outreach. The GP network provides early diagnosis and initial management of headache, with improved skills and confidence gained from a period of training at the MCOE. This will be supported by an ongoing education, mentoring and case discussion program conducted by a mix of face-to-face meetings and teleconference.

¹ The Alfred Hospital currently run the largest public headache clinic in Australia, with 4 Headache-trained neurologists (expanding to 6 in 2020) providing approximately 40 hours of headache outpatient care weekly, including an injectable therapies clinic for botulinum toxin and cranial nerve blocks. The clinical service supports the only Headache Fellowship for Neurology in Australia, inpatient therapy where required, and an active clinical trials program. A Headache Nurse will joining the service in 2020.

Outcomes

The goal is to make migraine care easily accessible, and as identifiable as asthma or diabetes, with a similar approach to acute and chronic management plans, and clinician confidence.

This proposal will deliver a robust feasibility assessment and business plan for a clinical centre of excellence with a group of neurologists with subspecialist training in migraine, providing care for the most complex migraine cases; training and fellowships for neurology trainees; 3-month secondments at the MCOE for GPs interested in developing migraine management expertise; the development of a clinical nurse specialist in migraine; conduct clinical trials and original research; develop local and international collaborations for research and clinical care.



Costs: \$100,000

over one year for the development of a business plan, with a further proposal to follow for implementation based on the business plan.

A sustainable model of quality migraine care for the Australian context, incorporating:

1	Centre of clinical and research excellence
2	Specialist GP network
3	Rural & remote service delivery for equitable access to care
4	Multidisciplinary care provision
5	Broad engagement in research and clinical trials
6	A migraine care pathway and management plan

It will also deliver a group of upskilled GPs with improved confidence and skills for accurate migraine diagnosis, appropriate initial management and rational use of expensive imaging or other medical tests. This will ensure earlier access, diagnosis and initial treatment of migraine through the headache GPs with a Special Interest (GPSI) network; reduced utilisation of emergency services; reduced unnecessary duplication of MRIs for migraine; safer use of medications for migraine and a reduction of inappropriate medicine use; early review of complex and severe cases through links with MCOE; ongoing education and support of this group through fortnightly telehealth meetings across the network.

The MCOE will also help reduce the burden of chronic migraine in Australia via an improved patient satisfaction and quality of care; a reduction in absenteeism / presenteeism through better migraine management, with cost savings to the community and social gains through family and social engagement. Family gains will be delivered through better parental health and ability to provide care and support to family, especially children who often suffer when parents suffer frequent migraine attacks (reducing transgenerational disability).

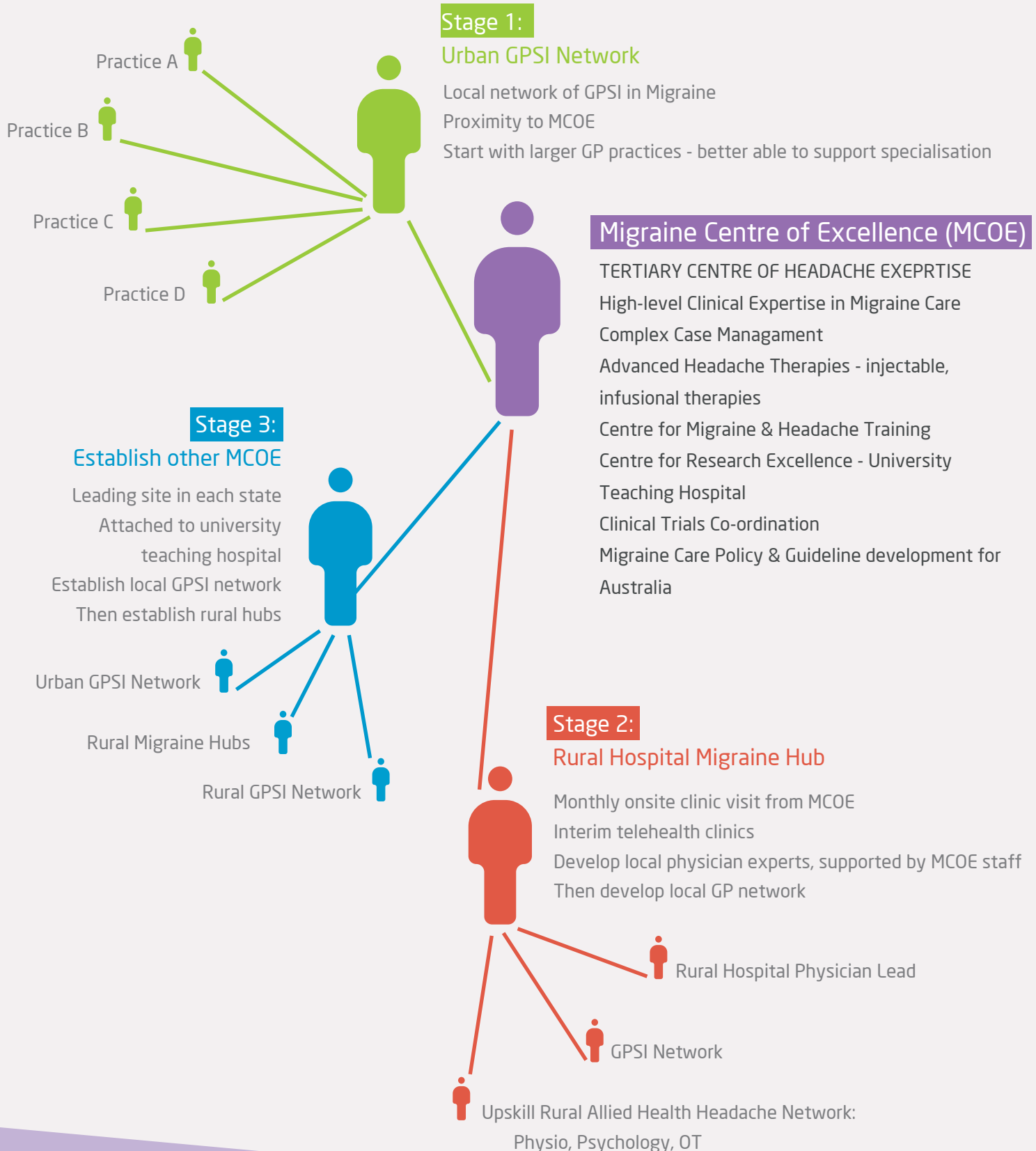
Upskilled GPs

with improved confidence and skills for accurate migraine diagnosis, appropriate initial management and rational use of expensive imaging or other medical tests

Australian Migraine Network

A Model for Excellence for Clinical Care & Research

Quality Migraine Care for All Australians |
Supporting Education and Training | Framework for Research Excellence



Proposal 4:

Migraine study to prioritize focus areas and maximise impact



Problem: To date there has been no in-depth epidemiological study to understand migraine, its burden, treatment and cost in Australia.



Solution: Support a pilot chronic migraine epidemiological study as a basis for assessing the burden of migraine in Australia.



Impact: Improved information to quantify the impact of chronic migraine in Australia will help identify priorities and facilitate translation into policy and practice.

Background

Australia is one of the only OECD countries which has no proper detailed and robust research studies assessing the epidemiological impact of migraine on the Australian society and economy. A few small, Australian studies suggest the burden of migraine is high and constitutes a major public health issue, but more detailed information is required.²²

The World Health Organisation has found that migraine is underdiagnosed, undertreated and poorly managed even in first-world countries like Australia.²³ We do not have Australian-based evidence to reveal to what extent migraine is underdiagnosed and poorly managed.

Without basic epidemiological research about migraine in Australia we are unable to clearly identify the gaps or quantify the true impact of migraine in Australia. Better data will assist in targeting policy and practice to areas of greatest potential gain.

Proposal

A pilot trial of the **Headache-Attributed Restriction, Disability, Social Handicap and Impaired Participation (HARDSHIP)** questionnaire in an Australian sample is the critical first step in obtaining data which will be invaluable to future research, practice and policy on chronic migraine in Australia.

The HARDSHIP questionnaire was designed by 'Lifting the Burden' and the Expert Panel in conjunction with the World Health Organisation and the 'Global Campaign Against Headache'. It is specifically designed for administration by trained lay interviewers for assessing the prevalence and burden of migraine. It has been translated into several languages and used in many countries and cultures. It includes a diagnostic module based on The International Classification of Headache Disorders, 3rd Edition beta (ICHD-III beta) which has been validated against headache specialist diagnoses in multiple languages and settings but not, as yet, in Australia.

Results of this study will help establish that the HARDSHIP questionnaire, administered via telephone survey, is suitable to assess prevalence and burden of chronic migraine in Australia. The results will provide invaluable pilot data to be used in future applications to National Health and Medical Research Council (NHMRC), and other funding bodies, for funding to conduct the first Australia-wide, comprehensive study of the epidemiology of chronic migraine. At present, accurate knowledge of the scope and scale of chronic migraine and its burden does not presently exist for Australia, despite the fact that almost certainly migraine, in its various forms, is a major health issue in this country as it is across the world. Understanding the magnitude of this problem is the first, crucial step in planning future research and in shaping practice and policy on chronic migraine in Australia.



Cost: \$96,000 to fund a pilot study.

Improve access to effective medicines to prevent migraine



Problem: A new generation class of treatments designed to prevent migraine attacks has been recommended for listing on the Pharmaceutical Benefits Scheme (PBS), but with unrealistic cap restrictions. Without adequate funding through the PBS, most patients with chronic migraine will continue to suffer unnecessarily due to poor access.



Solution: Increase PBS funding for new class of Calcitonin Gene-Related Peptides (CGRP) antibodies which are effective in migraine prevention.



Impact: Reduced burden of chronic migraine through provision of a proven safe, effective and cost efficient treatment specifically designed to prevent migraine.

Background

A class of treatments have recently been approved by the Therapeutic Goods Administration (TGA) representing a new generation in chronic migraine treatment. The treatment class consists of monoclonal antibodies that target CGRPs, which are involved in the cascade of a migraine attack. This is the first medical treatment specifically designed to prevent migraine attacks. Apart from this class, all TGA approved migraine preventive treatments were originally designed for other conditions. Multiple research studies have demonstrated the efficacy, safety and cost

effectiveness of this treatment. It has provided hope to many Australians struggling with chronic migraine, and has been described as “life-changing” by some of those who have been granted early access.

There is no cure for migraine, and patients respond differently to each treatment, which is why having more proven safe and effective options is critically important.

The cost of CGRP treatment without PBS support is between \$300 - \$800 per month per person. This is beyond the affordability of most people living

with chronic migraine, particularly given that the nature of chronic migraine makes work difficult or impossible for many people.

The Pharmaceutical Benefits Advisory Committee (PBAC) has recommended approval of the new CGRP antibody for migraine from at least one manufacturer but with strict cap restrictions that will severely limit its availability to the group of chronic migraine patients who need it most.

Proposal

Increase PBS funding for CGRP treatment to allow for fair and affordable access to proven and cost-effective chronic migraine prevention. Ideally, this involves creating a separate cap for this new generation CGRP treatment class.

A cap of funding was recommended by the PBAC to include the currently available treatment of Onabotulinum toxin-A (Botox). In clinical practice, Botox and CGRP monoclonal antibodies are considered separate therapeutic options. One Australian case series of Erenumab (a CGRP treatment) in the real world, found that patients failing Botox could still be responders (greater than 50% improvement) to Erenumab, which supports the different mechanism of action.

If considered under the same cap as Botox for PBS, the cap would need to be significantly increased in number to allow for the fact that some patients would try one treatment, such as Botox for at least 6 months, prior to trying the next treatment, such as a CGRP monoclonal antibody, for at least 3 months.

Australia's peak headache and migraine clinical organisation is the Australian and New Zealand Headache Society (ANZHS). The "ANZHS council strongly advocates approval of the CGRP monoclonal antibodies, in the use of migraine prophylaxis" (prevention). ANZHS also stated in a submission to the PBAC that this new class of treatments "will hopefully improve access and equity in receiving more effective treatments for migraine prophylaxis".

ANZHS continued: "Ideally, there could be a separate cap for Botox and CGRP monoclonal antibody therapies, in view of their different mechanisms of action and different patient groups responding clinically. In this case, the CGRP monoclonal antibody therapies would need a cap at least as satisfactory as the existing initially agreed Botox cap."

Migraine & Headache Australia, the ANZHS and the consumers are united by the urgent need for better treatments. The community advocated in record numbers to support the application of the CGRP antibodies onto the PBS. Over 2,000 public submissions have been made over the past 18 months to support the PBS application of these new generation treatments.

This is the **first** medical **treatment** specifically designed to **prevent migraine** attacks

There could be a **separate cap** for Botox and CGRP monoclonal antibody therapies



Cost:

\$50-75 million pa.

CASE STUDY:

(continued)

The potential to **IMPROVE LIVES** and **STREAMLINE TREATMENT** through migraine **PREVENTION MEDICATION**

Fiona Jeffery, Canberra, ACT

“When I read the information from Headache Australia stating that the new class of treatments were now under consideration for the PBS, I sobbed. Sobs of joy that finally there might be some light at the end of the tunnel, sobs of hope that I might get my life back, and sobs of relief that there wasn't too much longer to wait. To have a treatment that is specific to migraines and will not leave me with the side effects that the other medications do, and even more, to have a treatment that I can have once a month and for the rest of the time feel like the normal, healthy person I used to be is something that I would sacrifice my material possessions for. But to have this made affordable on the PBS would be life-changing. It would give me a chance at returning to my previous working life, and allow me room to pay for the extra medical expenses that mount up weekly, such as vestibular physiotherapy,

audiologist (hearing aid, hearing tests), psychologist, hyperacusis treatment, medications, specialist appointments, GP appointments, etc.

My husband and I have used up tens of thousands of dollars in savings in the past few years trying to keep up with my spiralling medical expenses, but despite cutting back personal expenses to the point where we were only spending on medical items, we have now reached the point where we cannot afford all the treatment recommendations and have to space out timings and reduce treatment frequency.

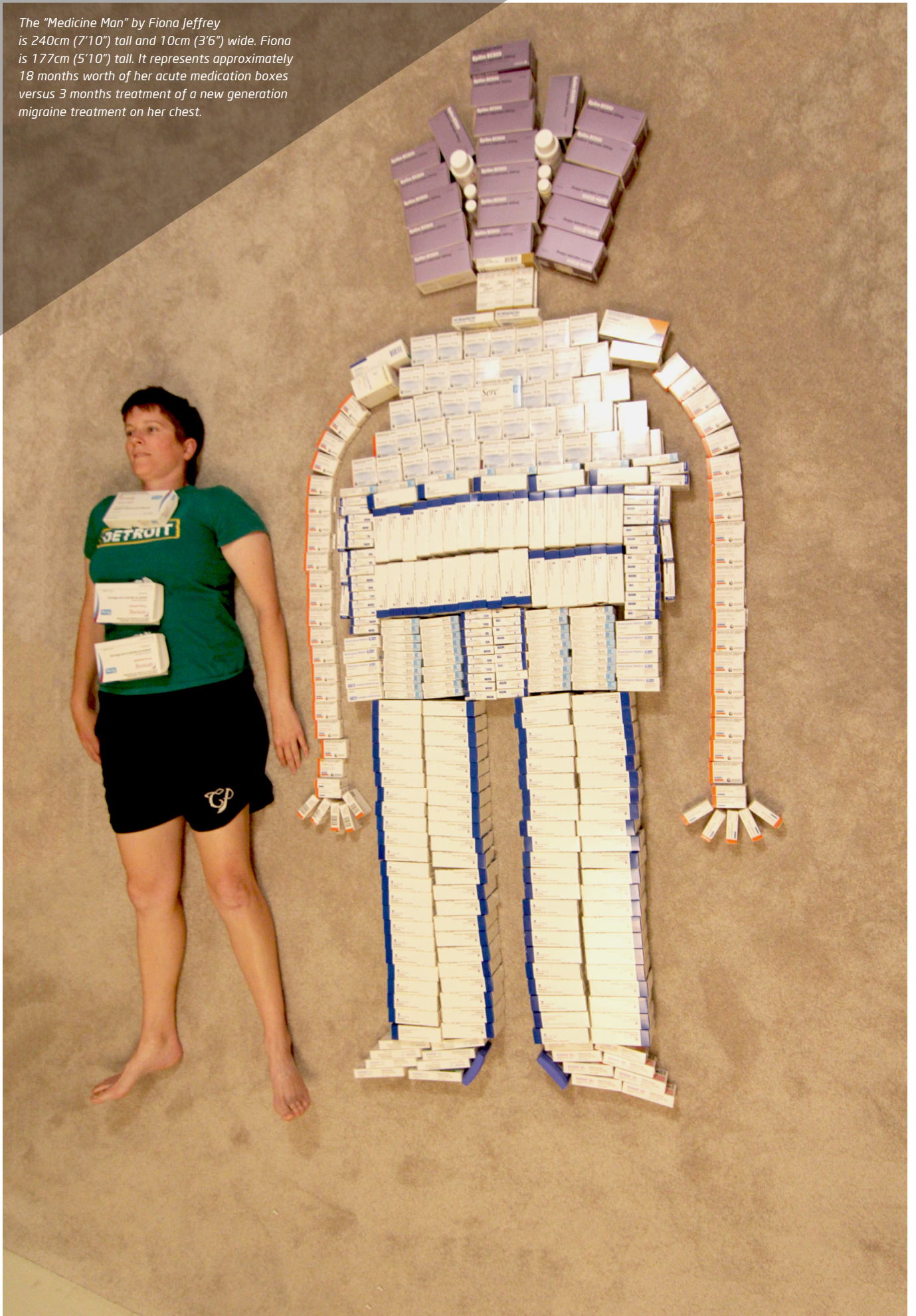
From an economic standpoint it makes sense for this treatment to be covered on the PBS for so many reasons. Migraine is such a debilitating disease. You become completely unable to function and help yourself. From being a productive worker, an active carer for my nephews and family, a community

citizen in local sporting organisations, and a partner at home, I went to being unable to work, on income insurance (so a drain on work and insurance resources; being cared for by family and friends, unable to participate in the community (and more likely to be a drain on community support resources), being cared for at home (in a very unequal partnership), and a drain on the medical system. The benefits of funding this medication on the PBS would be more than paid for by the societal productivity gains associated with having patients with migraine and their carers functioning as healthy members of the community.

The introduction of this treatment on the PBS will, quite literally, mean the world to me. It will change the world for the better for all Australians with chronic migraine, their families, their friends, and their treatment providers.”

“to have this made affordable on the PBS would be life-changing. It would give me a chance at returning to my previous working life”

The "Medicine Man" by Fiona Jeffrey is 240cm (7'10") tall and 10cm (3'6") wide. Fiona is 177cm (5'10") tall. It represents approximately 18 months worth of her acute medication boxes versus 3 months treatment of a new generation migraine treatment on her chest.



Revenue measures

The total financial cost of chronic migraine in Australia is estimated at \$8 billion according to a recent report.⁹

Given the magnitude of current Federal Government expenditure on health and welfare system costs related to migraine (\$704 million²⁴), there is significant potential to make savings to the Federal budget by improving the management of chronic migraine in Australia.

Key areas where Federal Government health and social welfare budget savings can be made include:

- Reduction of avoidable repeat GP attendances for management of chronic migraine, through improved assessment and treatment
- Reduced reliance on pharmaceuticals including opioids
- Reduced social welfare outlays resulting from increased workforce participation by people with chronic migraine, and reduced reliance on Disability Support Pensions.

If the proposals in this budget submission lead to even a modest 20% saving in Federal Government health expenditure related to migraine, the savings will add up to over \$150 million per annum, far outweighing the expenditure proposals outlined in this submission.

In addition, there will be significant savings to other parts of the health system, including those funded by state and territory governments and by individuals; and to the economy more broadly.

Federal Government expenditure on health and welfare system costs related to migraine is **\$704 million**

The savings will add up to over **\$150 million per annum**



Why Migraine & Headache Australia?

Migraine & Headache Australia is the only charitable organization in Australia that aims to support the more than 5 million Australians affected by headache and migraine disorders. Our mission is to provide reliable information, advocate and support for the patient community.

Migraine & Headache Australia is a division of the Brain Foundation. The Brain Foundation was established in 1970 by members of the Australian Association of Neurologists and the Neurosurgical Society of Australasia to reduce the incidence and impact of brain, spine and nerve disorders, diseases and injuries through the provision of support, community education and research. Over the past 50 years the organisation has provided funding to researchers totalling more than \$5 million from charitable donations. Research grants for migraine and other neurological conditions are awarded by an independent medical review board.

Migraine & Headache Australia has close relationships with professional migraine and headache organizations such as the Australian and New Zealand Headache Society (ANZHS), the Australian and New Zealand Association of Neurologists (ANZAN), and the International Headache Society. Strong relationships with other migraine patient organizations globally include the American Migraine Foundation, National Headache Foundation (USA), the Migraine Trust (UK) and Migraine Canada. Migraine & Headache Australia is also part of a Global Patient Advocacy Coalition (GPAC) led by multi-stakeholder group of leaders from the clinician, research, patient and advocacy community in migraine.

The Migraine & Headache Australia website receives an average of 45,000 page views per month, or half a million per year. Migraine & Headache Australia has also developed the National Headache Register made up of mostly patients living with chronic migraine who subscribe to receive regular updates about new research, treatments, events and news for migraine and other headache disorders. The National Headache Register has 12,500 subscribers. With additional resources Migraine & Headache Australia can build on a strong foundation to reach a larger proportion of patients who are suffering in silence without help. Our goal is 100,000 subscribers and 100,000 web visits per month to expand awareness and disseminate informative resources.

Migraine & Headache Australia also has proven experience in promoting awareness to the patient community. For example, Headache and Migraine Awareness Week receives annual press and media coverage. Frequent contact and access to leading medical societies such as ANZHS and ANZAN ensures our content is medically reviewed and distributed.

With the knowledge of clinicians, researchers, and patients as well as a network of consumers, Migraine & Headache Australia is well placed to implement these proposals on a strong foundation of patient and expert support, trust and awareness.



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