

MY MIGRAINE VOICE

A survey of people with frequent and severe migraine*

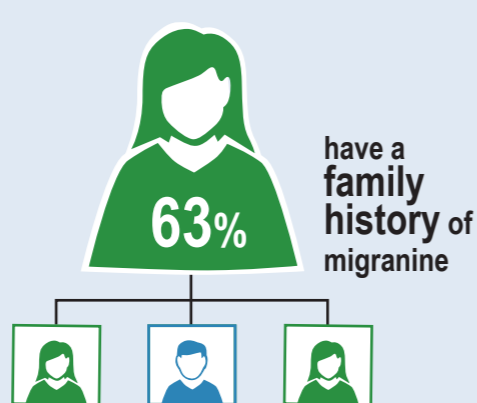
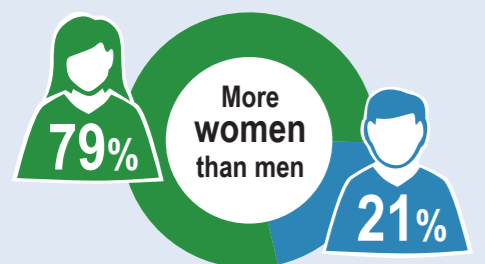
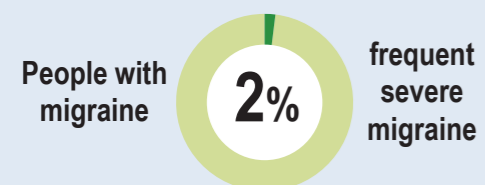


* A small subset of people with migraine who have had at least 4 migraines per month for 3 months



Survey population: people who had 4 or more migraines per month, for the previous 3 months

About people with frequent migraine



Migraineurs suffer from other chronic conditions such as

- ✓ anxiety
- ✓ depression
- ✓ insomnia
- ✓ chronic pain

Use of healthcare resources

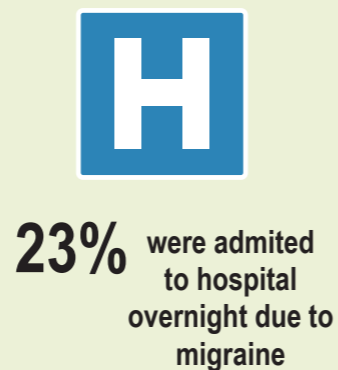
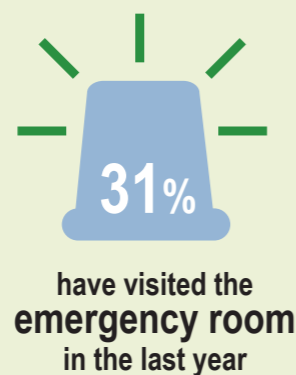
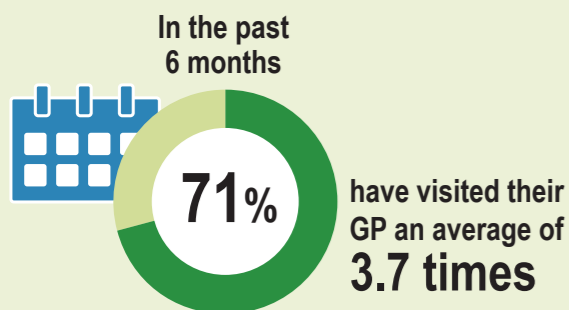


8 out of 10 people visit a GP about migraine

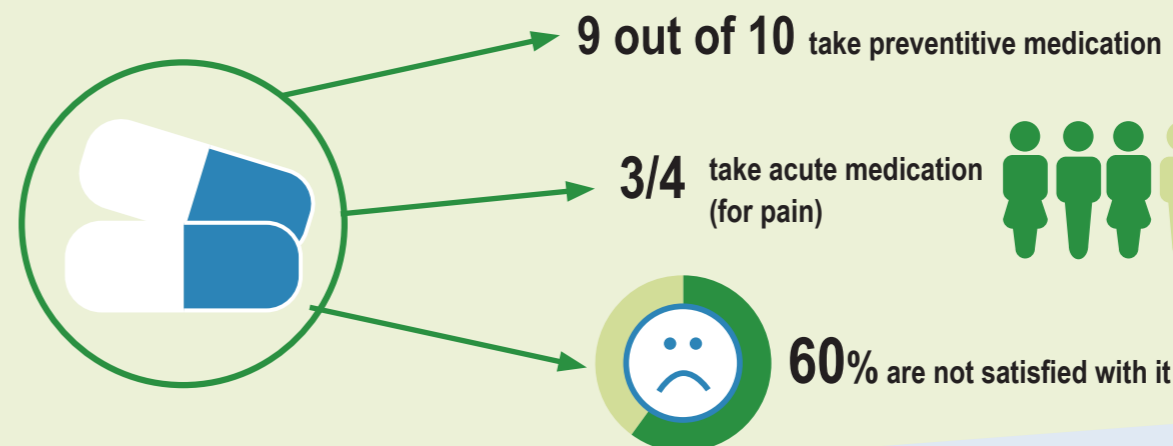
The diagnosis is made by a GP in only



Almost **7 in 10** have had a brain scan



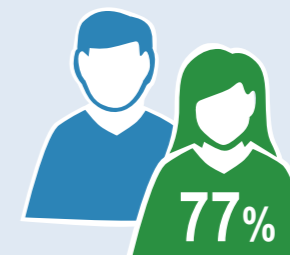
How frequent migraine is treated



Living with frequent migraine

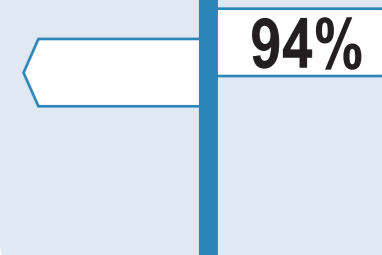


In almost **3/4** of cases attack last **more** than a day

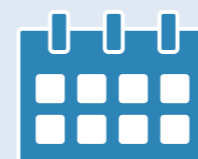


Migraine impacts **relationships**

social life



Average hours in isolation or darkness per month: **31.8**

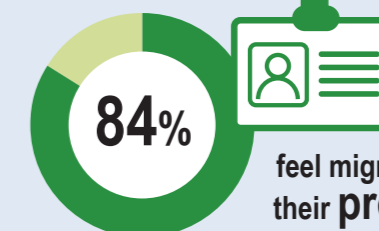


are **fearful** of their next migraine attack

Average migraine pain



7.9/10



feel migraine has impacted their **professional life**



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Foreword Introduction

It is with great pleasure that I provide the foreword to this landmark report on the true burden of this dreadful condition. Like many complex neurological disorders, our knowledge of the biology of migraine has improved over the years. Yet away from the laboratory, the visceral impact of the condition on people's relationships, careers, families, and everyday lives often lacks understanding. Far more than just a headache, it is of note that the World Health Organisation (WHO) has recognised the impact of migraine worldwide; they list it as one of the top 20 causes of disability among adults of all ages, and it is ranked as number four among women. Although we generally tend not to associate children and adolescents with headaches, they suffer too, their migraine frequently misconstrued as avoidant, challenging, unsociable, inattentive, or oppositional behaviour.

Chronic migraine is a pattern of having headache on 15 or more days every month so it is hardly surprising that many sufferers become psychologically overwhelmed, anxious and depressed. Not only is the pain disabling when it occurs, but between episodes, migraine sufferers spend much time trying to manage their lives so as to reduce the frequency, severity, intensity and duration of attacks. The bidirectional relationship between chronic migraine and psychological distress also highlights the importance of the provision of timely psychological support.

Overall, the multidimensional nature of migraine calls for a multidisciplinary approach. This is the best approach for the person with migraine. Interventions may include the support of the general practitioner, neurologist, psychologist, pharmacist, nurse, specialist, psychiatrist,



speech and language therapist, physiotherapist and systemic family therapist. Such a multidisciplinary approach would also be useful when researching prevalence, impact, treatment and triggers of migraine and its management.

The goal is that the data gathered in this report will help to inform policymakers and the wider public about the true personal cost of migraine pain. The Irish data forms an important part of the larger global survey undertaken by Novartis in partnership with the European Migraine and Headache Alliance and allows us to contextualise the impact that migraine can have on our society and economy.

I would like to take this opportunity to thank the participants who took part in this survey for helping to paint a clear picture of the debilitating and often devastating reality of migraine. I also commend the Migraine Association of Ireland for their diligent work in highlighting and bringing awareness to this oft-misunderstood condition. Those of you reading this report who experience migraine may feel vindication in seeing your own experience come through in the findings of the survey. For those of you with no prior experience of migraine, I hope you finish it with an enhanced understanding and empathy for those who do.

Dr Marie Murray,

Clinical Psychologist PhD, M. Psych. Sc. B.A (Psych), C. Psychol. PsSI, Reg, FTAI, ICP, EAP

Introduction



Migraine is a complex neurological condition that is classified by the World Health Organisation as the seventh most disabling disease worldwide, and the fourth for women.

The most common neurological condition in the world, it is estimated to affect about 12-15% of people, meaning that up to half a million people in Ireland suffer from the condition.¹ While it affects all age groups, it is three times more common in women than it is in men, with a significant hereditary component. A highly individual condition, some people may experience only one or two attacks per year while others will suffer on a regular or weekly basis.²

Migraine generally features a one-sided throbbing headache that is episodic and lasts hours or even days with total freedom between attacks. The headache is normally worsened by movement or routine physical activity. An attack can last anything from four to 72 hours.³

Classical Migraine (migraine with aura) may be signalled by visual disturbances in what is called the "aura" stage.⁴ This affects about 20% of migraineurs. Common migraine (or migraine without aura) and classical migraine may be accompanied by nausea, vomiting, diarrhoea, confusion and, in rare cases, temporary paralysis and loss of speech. Sensitivity to light, noise and strong smells is also frequently reported.⁵

Despite its high prevalence, migraine remains a misunderstood and under-managed condition. Delays in diagnosis are common. As well as the individual impact on quality of life, the condition can affect family and relationships.⁶ The duration/frequency of migraine attacks means there can also be a significant impact on a person's working life, potentially affecting their earnings and career progression.⁷

Survey

In a bid to understand the true patient burden of

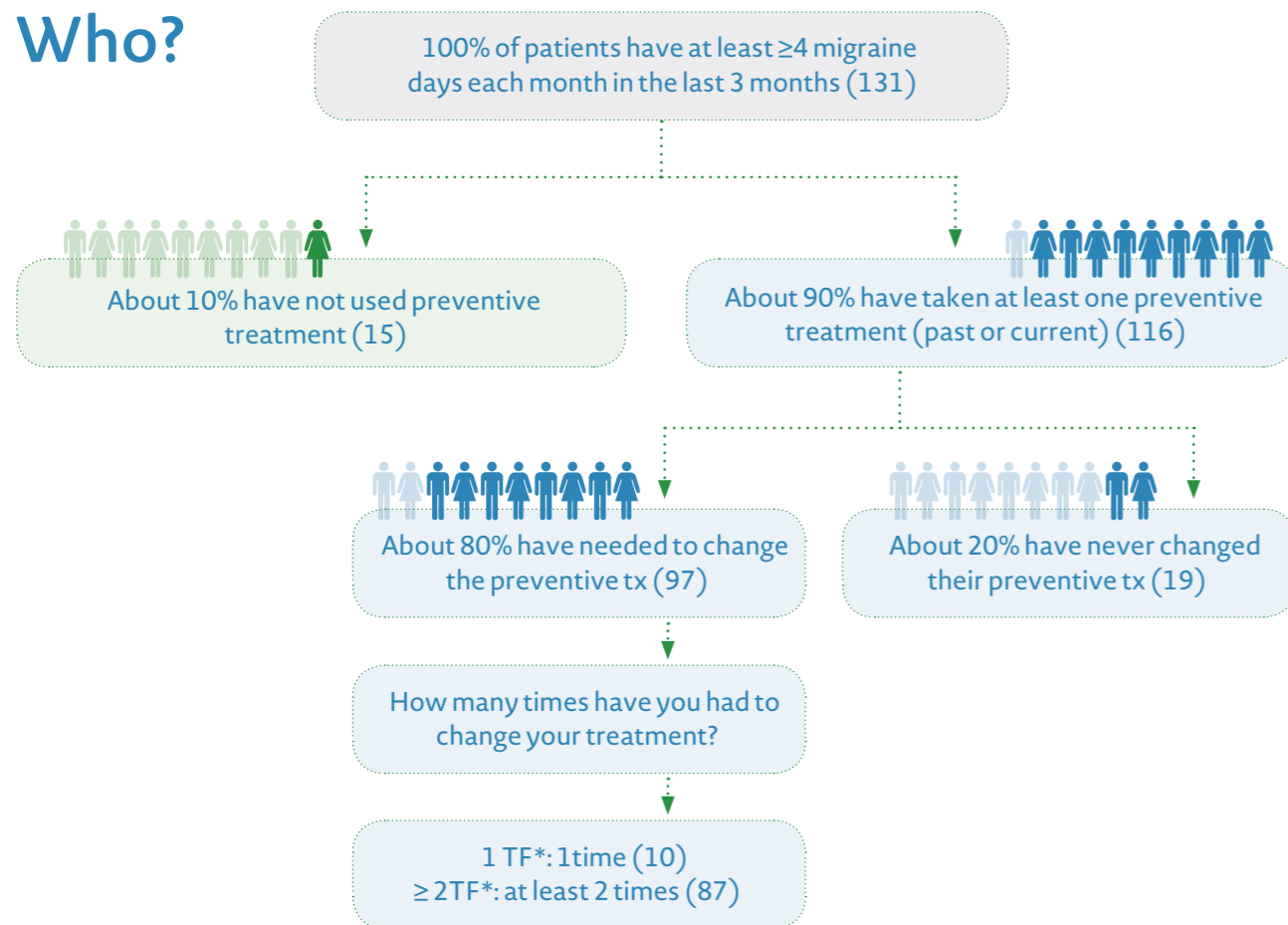
migraine, Novartis embarked on a large-scale global patient and caregiver survey in 2017. A total of 10,235 people in 36 countries participated. The goals of the survey were to:

- Understand episodic and chronic migraine patients – what is the true burden of disease?
- Understand the patient journey, from diagnosis to treatment
- Identify barriers and hurdles in everyday life
- Learn more about the economic impact
- Understand the emotional burden

The survey aimed to elucidate how migraine affects daily life and how much support is needed on daily basis, with a strong focus on relationships, professional life, and hobbies. It was also designed to explore the main barriers to accessing effective treatments, both medical and emotional, as well as attempting to quantify the economic burden of migraine.

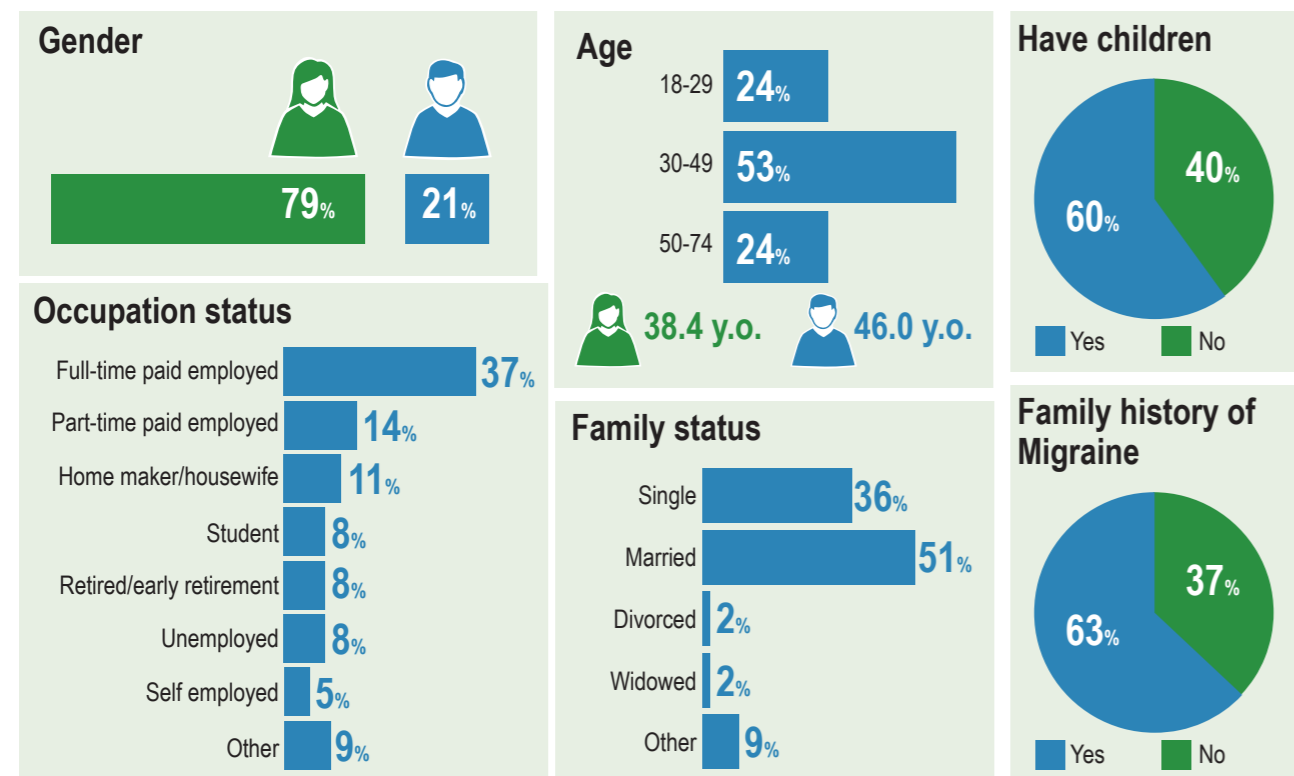
A significant number of people have migraines. However, a small subset have frequent and severe migraine and this survey addressed that group. The Irish arm of the research involved 131 participants, who were recruited from online panels and the patient organisation. It took place between September 2017 and February 2018. To participate, patients must have had four or more migraine days each month within the previous three months. It is hoped that the information gathered will serve to provide up-to-date data on the personal impact of migraine and the potential requirements for migraine support and services.

Who?



*1TF: Migraine patients who have failed 1 preventive medications, 2+ TFs: Migraine patients who have failed at least 2 preventive medications

About people with migraine?

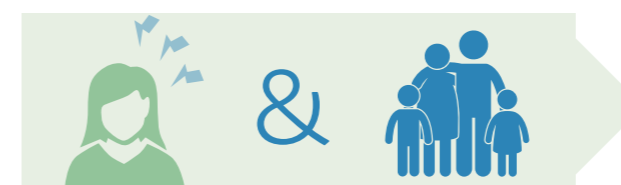


Executive Summary

This survey has, for the first time, outlined the severe personal, professional, societal, and economic impacts of migraine.



Significant **gaps in healthcare services** when it comes to migraine have been identified. **Delayed diagnosis** is common, and patients report delays in being referred to specialist consultants or headache clinics.⁸ There is limited management of migraine at primary care level, something that needs to be addressed.⁹ Although the vast majority of patients take medication to prevent and treat their migraine, there are mixed levels of satisfaction, suggesting generally **poor control of the condition**.¹⁰



Migraine also takes a significant **emotional toll**. Relationships with family and friends are severely affected by migraine, as sustained and regular attacks affect participation in everyday activities and social events.¹¹ Patients report spending an average of **32 hours every month in isolation or in darkness**. Psychological and social supports are shown to be inadequate.



This is not withstanding the health budgetary impact. **Emergency department visits and hospital admissions are common**. Poor control of migraine at primary care level has knock-on effects throughout the entire health service.



Migraine attacks last several days, and the survey shows that many migraine sufferers in part-time and full-time employment are not in receipt of sick pay for work days lost to migraine. Unsurprisingly, migraine sufferers say the impact their condition has on their career and professional lives is significant. Clearly poor control of the condition has a wider impact on the economy, in terms of lost productivity and absenteeism.



The Headache Pathway, an integrated programme of care, is part of the HSE Clinical Care Programme for Neurology and was launched in 2016.¹² The Pathway, which emphasises multidisciplinary care and suggests staffing and resourcing in line with best practice, contains a number of recommendations that would serve to address the current gaps in care for migraine patients, yet this has not been funded or implemented to date.¹³

Patient Story

Louise O'Sullivan



Louise O'Sullivan is a 29-year-old from Cork who works in residential sales

Your first experience of migraine can be frightening because you haven't gone through it before.

"Then future ones can be frightening because you know what's potentially ahead of you."

For me, that was what it felt like. Fear and panic amongst the physical symptoms of nausea, numbness and throbbing pain.

Many migraines later I've managed to level off my fear at the onset of attacks. I have a ritual now that works for me and that I stick to. Once I feel the visual aura starting, I immediately take my medication. I get plenty of water and find as quiet and private a space as possible. This is fine if at home but can become more challenging when out and about. Once I've managed this much (and even this can be challenging depending on how quickly the migraine escalates) I sit down, close my eyes and very simply try to breathe deeply in and out. I reassure myself, sip water, and just breath to distract myself as much as possible from the physical symptoms.



Once my mind is calm I find that I'm far better equipped to manage the migraine itself.

This has taken some getting used to as my initial response has always been panic. At times I would be angry with myself and my body for getting a migraine. Now I try to practice more patience and self-compassion. We all know the battle of trying to balance triggers so it's easy to blame ourselves if an attack strikes. I further support myself emotionally by making a conscious effort to just be kind to myself especially in the days after the migraine. I go walking, I eat well and get good sleep or even just relax with a good film. The events organised by the Migraine Association also offer a huge amount of support. Migraine can be isolating as colleagues and friends may not fully understand so attending these events with other migraine sufferers can be a fantastic way to support yourself emotionally also.

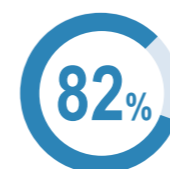
Patient journey

From first diagnosis to current management

Who provided your diagnosis?

An overwhelming majority of participants (82%) said they turned to their GP when it came to initially seeking advice about their migraines. Despite this high level of engagement, just 38% of patients received a definitive diagnosis of migraine from their GP.

Ireland's limited number of headache specialists is reflected in the 2% of patients who saw one initially, and the 11% of patients who ultimately received their diagnosis from one. Just 1% of patients first spoke to a nurse about their condition but none received a diagnosis in this way.



initially sought advice about their migraines from their GP

While just 7% of participants initially sought help from a neurologist, specialists made the vast majority of diagnoses among the survey cohort – 44%.

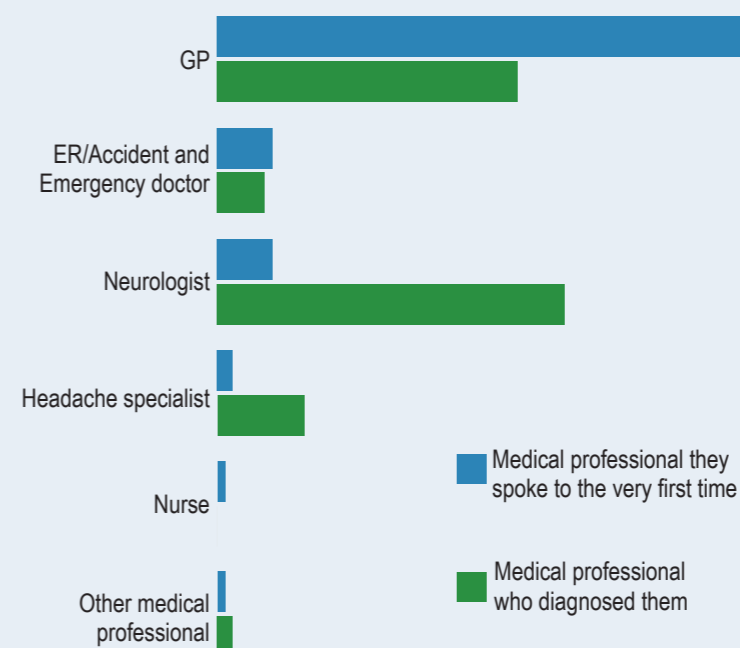
In an indication of how serious a migraine attack can be, doctors in the emergency department were the first healthcare professional a patient spoke to about their condition, and also the first to diagnose them, in 7% and 6% of cases, respectively.

How long did it take you to receive a diagnosis?

Just over a quarter (26%) of participants said they received a migraine diagnosis within one month, while the same proportion waited between one and six months to be officially diagnosed. A further 15% of respondents took between 7-12 months to be diagnosed, and for 13% they waited between 1-2 years. For a staggering 20% of patients there was a delay of more than two years before their diagnosis was made.

Patients saw an average of 2.4 healthcare professionals before receiving a diagnosis – for those diagnosed within one month this was 1.3, but for those waiting longer than two years it was 3.1.

HCP patients talk to the very first time vs HCP who made diagnosis



Unsurprisingly, the number of appointments before diagnosis increased with time – patients diagnosed within a month had an average of 1.6 appointments but by the time a patient was waiting two years or more, they had attended an average of 6.7 appointments.

Who manages you? What do they discuss?

For almost half of patients (44%), their migraine is managed in the primary care setting. A further 28% are under the care of a neurologist, with 11% seeing a headache specialist regularly. A small number (2%) see a nurse or other HCP, respectively. A worrying 9% of participants say they take personal responsibility for managing their migraine, while a further 4% report that no one is responsible for the management of their migraine.

It was also evident from the survey results that patients encounter a wide range of healthcare professionals, as well as alternative practitioners. When asked who they had seen in the past six months, the GP was the most common answer, with 71% of respondents saying they had visited their GP an average of 3.7 times. This was followed by the neurologist (42%), pharmacist (27%)

44% of patients had their migraine managed in the primary care setting

and headache specialist (24%). A significant proportion of patients also visited a dentist or physiotherapist during this period. Ten per cent of patients had seen a nurse in the past six months. Other clinicians seen included ENT specialists, rheumatologist and psychiatrists. Alternative practitioners seen by patients included chiropractors and Chinese medicine specialists.

According to patients, a wide range of topics are typically discussed during these monitoring visits. The average number of answers selected by each respondent was 4.7, indicating a broad discussion with the relevant professional regarding multiple aspects of migraine. The vast majority of patients (81%) discussed treatment options at each visit. Coping with symptoms, and the use of migraine diaries for recording headaches, symptoms and triggers were also frequently discussed.

Importantly, practitioners appeared to regularly speak to patients about the impact of migraine on daily activities, social life, and professional life. More practical topics such as financial support and advice, and access to further information were covered less frequently.

How long does it take to get an appointment? How long did it take you to get a brain scan (CT or MRI)?

The GP or primary care practitioner remains the most accessible healthcare professional for patients – 47% of respondents reported being able to secure an appointment within 24 hours. While 29% said this may take a few days, and 10% said it could be up to one week, this pales in comparison to waiting time for neurologist appointments. Almost one-quarter (24%) of patients said they waited over four months to see a neurologist, although some 13% of patients are seen by a specialist within one week. One-in-four patients said they do not see a neurologist or any other specialist.

Two-thirds of patients reported having had a brain scan, for example a CT (computerized tomography) or MRI scan (magnetic resonance imaging). Patients were more likely to have received a brain scan if they had a treatment failure. A significant proportion of patients said they had more than one, and this number rose in relation to treatment failures.



Two-thirds of patients reported having had a brain scan, for example a CT (computerized tomography) or MRI scan (magnetic resonance imaging).

Patient Story

Mel Farrell



Mel Farrell is a lecturer and researcher in his thirties

I have suffered from debilitating and severe migraines for most of my life. One of my earliest memories is waking one early summer morning, in a bed or cot, when a chink of bright sunlight shone through the gap in the curtains and triggered a severe headache. I can only have been about three or four years old but I distinctly remember the pain, and it was the same pain I have associated since then with migraine. I know from talking to my mother that I was brought to our GP at around age five and the issue was identified as migraine.

To this day I have male friends who simply do not understand. By a comment or look you sort of know that is one barrier that won't ever come down. I have to say that the situation is different with friends who have seen me with a migraine. One friend once had to drive me home from an event and he was in shock at the severity of what was happening.

I suffer from migraine with visual aura. In my younger days this took the form

of what I can only describe as a colourful version of 'TV static' – flickering, colourful snowy blotches that I would see in my peripheral vision. In adulthood it started to take on the appearance of zigzag pulsating lines that expand from the centre of my vision outwards. It's absolutely horrible.

"If I begin to suffer sensitivity to light and sound, it is often too late to take my medications and I realise I need to prepare for the onset of a migraine attack."

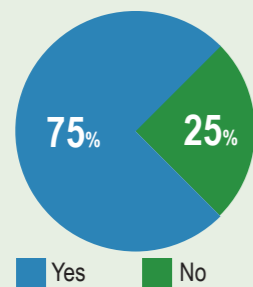
I have to retreat to a darkened room, to ready myself for the onset of a spreading pulsating headache. The pain is so bad that I can only text "Migraine" if people try to contact me. This period will be followed by nausea and vomiting for several hours. The headache can often ease then – as a child I would often welcome the vomiting as it brought such relief to the headache phase.



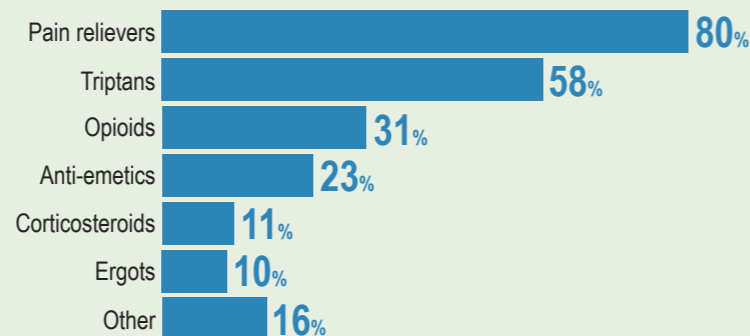
Current treatments & barriers to access

Patients use a broad range of medications, both preventative and acute, in an attempt to control their migraine. Yet **satisfaction levels are mixed**, suggesting a large proportion of people are not being adequately managed by their prescribed medication regimen.

Do they take any acute medication to treat migraine



Treatment



What types of acute medications are you taking for your migraine? Are you satisfied with these?

The vast majority – or 75% - of patients said they are taking some form of acute medication to treat their migraine. Of this, 84% are using medication prescribed by their doctors. Yet a significant proportion of respondents (60%) reported consuming over-the-counter medication. Almost a third said they turned to alternative or complementary therapies.

The survey findings also determined that a large number of respondents were combining two or more types of medications – a combination of pain reliever and triptan was the most common, with 26% of respondents reporting that this was their preference in the event of an acute attack. Some 13% used pain relieving medication in isolation, while 7% preferred using triptans. Opioids, anti-emetics, and corticosteroids were also used in varying combinations.

When it came to how long patients were using these acute medications, most reported using triptans and/or pain relievers for over two years. Despite this, satisfaction levels were mixed. When asked if they were satisfied with their medication to treat the symptoms of their migraine when experiencing an attack, just 7% agreed that they were “completely satisfied” with their current choice of acute medication. Some 44% said they were “somewhat satisfied”, but 18% reported being “somewhat dissatisfied” and a further 13% admitted they were “completely dissatisfied”.

Those who reported being somewhat or completely satisfied with treatment cited reasons such as ease-of-use, lack of/few side effects, rapid symptom relief, and affordability. In contrast, low satisfaction levels were related to factors such as slow onset of action, partial relief of symptoms, no symptom relief, and expense. A large proportion of this cohort stated they did not like taking too many tablets (55%), while a further 23% admitted they did not like taking their medication.

What type of preventive treatment are you taking? Are you satisfied with it?

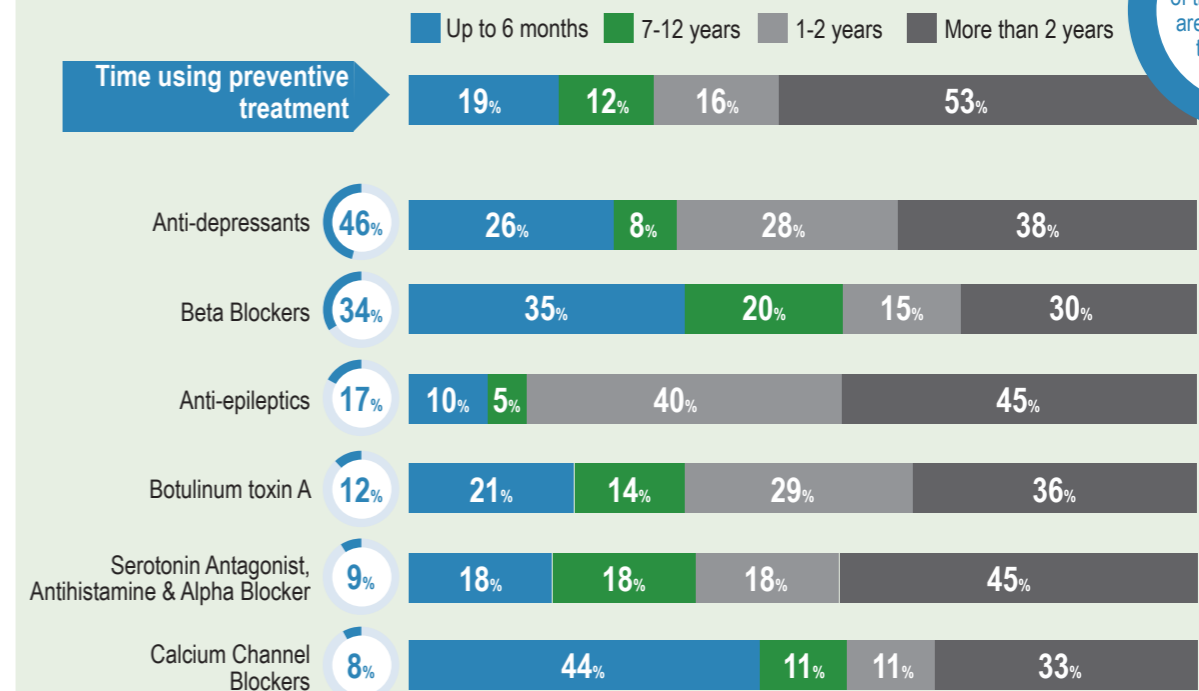
An overwhelming majority of survey respondents are taking some form of preventive medication – 89%. More than half have been using preventive treatment for more than two years.

Antidepressants were the most commonly used form of preventive treatment, with 46% of participants reporting their use. Just over one-third (34%) said they used beta-blockers, while 17% are taking anti-epileptic medication. Botulinum toxin A (“Botox”) is used by 12% of patients.

Again, satisfaction levels were mixed. While 7% reported being completely satisfied, and 34% said they were somewhat satisfied, 22% said they were completely dissatisfied, and 16% answered somewhat dissatisfied. Just over one-fifth said they were neither satisfied or dissatisfied.

Satisfaction levels were most frequently related to the medication reducing the intensity of a person’s

Treatment – Preventive treatment



89% of the respondents are on preventive treatment for migraine

symptoms, as well of ease-of-use and a reduction in the number of migraine attacks. Improved quality of life and affordability were also popular answers.

Respondents who said they were completely or somewhat dissatisfied with their choice of preventive treatment were most likely to attribute this to it not being a cure, or its failure to relieve symptoms. Too many side effects were another common issue.

Treatment failures and switching

Of the study participants, 10 patients had experienced

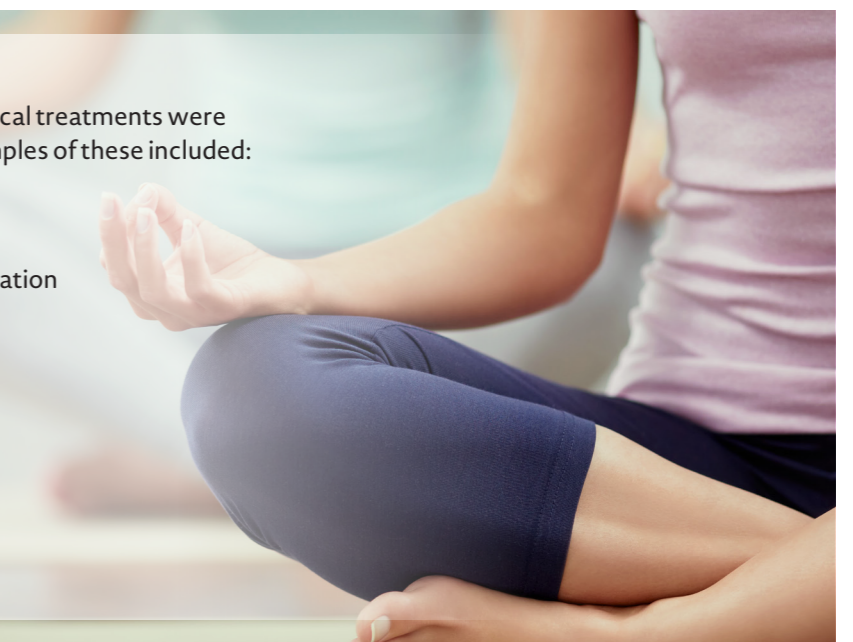
only one treatment failure. The most commonly cited reason was that the medication did not work at all, while other factors included too many side effects associated with the medication or a switch based on their doctor’s suggestion.

A large proportion of patients (87) had had two or more treatment failures. Again, the most commonly cited reason was that the medication did not work at all, although this was closely followed by too many side effects.

Other treatments

A wide range of non-pharmacological treatments were popular among respondents. Examples of these included:

- Diet and nutrition
- Lifestyle changes
- Vitamins and mineral supplementation
- Massage
- Breathing exercises
- Sleep hygiene
- Yoga/meditation
- Acupuncture
- Physiotherapy
- Counselling
- Homeopathy



Patient Story

Susan Haddon



I have suffered “headaches” from the time I was about three years old. I used to complain to my mother about pains in the back of my head, which was alarming for her since I was so young. Being adopted, I had no family medical history to work with. She was always concerned it was something more sinister than migraine, so once that was persistently ruled out over the years, we tried to manage the headaches as best we could. All these medical interventions were privately paid for, as accessing paediatric neurology services at that time was virtually impossible.

I wasn’t formally diagnosed with migraine until I visited the Migraine Clinic in Beaumont Hospital in my early twenties. This was after making contact with my birth family and discovering my strong genetic link to migraine. The wait to access this clinic was over a year at the time, but the care I received there was second to none. And once you’re in the system, it is easier to access follow-up care.

Unfortunately, many GPs seem either uninterested or uneducated about the finer aspects of migraine and this leaves

many patients in the dark about the condition in general and how to manage it. Organisations like The Migraine Association of Ireland are vital to help sufferers understand more about the condition and connect with others who can give hints/tips on how best to manage your migraines. I found the specialist nurse I met through MAI easier to access than other personnel in the Migraine Clinic, especially if I had a simple question to be answered. Because of wait times, I switched my main care back to a good GP who helps me manage with a mix of prophylactic and acute treatments. Luckily, I have not needed to see a neurologist recently, as I believe the waiting times continue to grow.

“There need to be more migraine clinics available to patients and there definitely need to be more neurologists who have an interest in migraine in public hospitals all over the country.”



What does it mean to live with the pain of migraine?

The responses to this question clearly illustrated the multi-symptomatic nature of migraine, with all participants selecting several symptoms from the list provided. The sustained nature of a migraine attack was also evident.

What are the symptoms you experience during migraine?

Unsurprisingly, headache was the most commonly reported symptom associated with a migraine attack, with 92% of respondents naming this as one of their key symptoms. Sensitivity to light closely followed, however, with 88% of survey participants saying they experienced this, while 86% reported feeling a severe “throbbing” pain in the head. The difference between migraine and headache was highlighted by the 82% of respondents who said it was a headache that did not go away after taking medication. Nausea, sensitivity to sound, severe pain on side of the head, neck ache, and visual disturbances were among the other frequently cited symptoms. Aura was a problem for 52% of those surveyed.

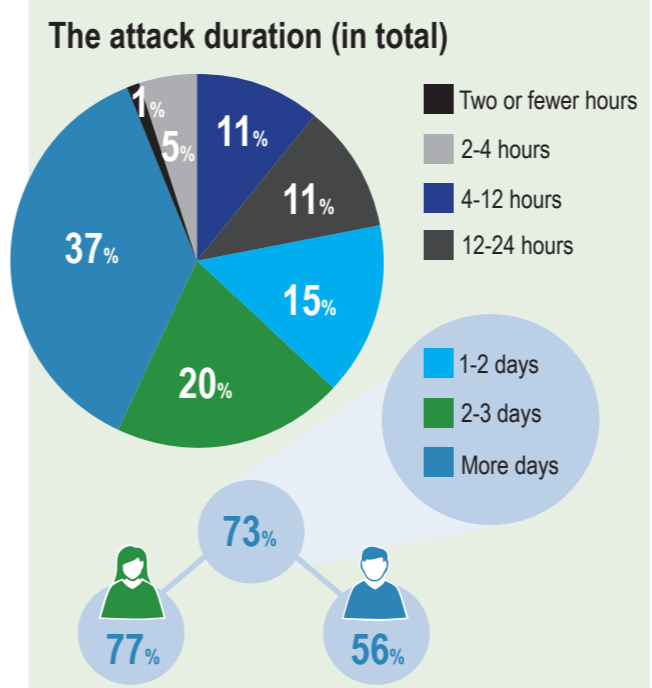
How long does your migraine attack last, from warning phase right through to being fully recovered?

This question highlighted the sustained duration of a

migraine attack, and the significant impact it can have on a person’s normal daily activities.

The vast majority of respondents said their migraine attacks lasted from 24 hours to several days. Over one-third of respondents (37%) said the attack lasted more than three days, from start to finish. A further 20% said theirs typically lasted 2-3 days, while 15% said it was between 1-2 days. Just 1% said their attack lasted less than two hours. Participants were also asked about the duration of the different phases of their migraine attack – before, during, and after. Some 23% reported feeling their migraine “come on” for more than one day. Forty-nine per cent said the attack itself lasted more than one day, and 47% said the after-attack phase lasted more than one day.

During the attack, 57% reported feeling extremely limited in terms of completing their daily activities, and 34% said they were very limited. A large number of respondents also reported feeling extremely or very limited before and after the attacks.



	Before the attack	During the attack	After the attack
Two or fewer hours	24%	2%	8%
2-4 hours	15%	7%	9%
4-12 hours	16%	23%	14%
12-24 hours	15%	17%	16%
More than 1 day	23%	49%	47%
I do not experience this	7%	3%	6%

Work-life balance

Migraine has broad socioeconomic implications. The extent of this was amply illustrated by the survey results, which showed the condition has an **overwhelmingly negative impact on career progression and earnings.**

What is the impact on your professional life? Does it affect your work and productivity?

Just over half of the survey respondents were in full-time/part-time employment or self-employed. Although three-quarters of respondents in full-time work said their employer was aware of their condition, just 28% of this cohort answered that they feel supported by their employer.

Unsurprisingly, the vast majority – 84% - said they felt their migraine had impacted their professional life. Common reasons for this included:

A number of participants said their migraine had caused them to change jobs (15%), 13% said they had changed profession/career path due to migraine, and 12% said they had lost their job because of their migraine.

Of those in some form of employment, 69% said

they had needed at least one day off in the past month because of a migraine attack. The average number of days missed in the past month was 6.9, although 12% of respondents said they had missed more than 14 days of work.

Yet this did not tally with paid sick days; on average, respondents received just 2.4 days paid sick pay. For 43%, there were no paid sick days, although 47% received between one and five.

What is the wider impact on the health service?

Hospital visits were commonplace for survey participants, with 31% reporting having visited the emergency department in the past 12 months. The average number of visits for this subset of respondents was 2.2. A total of 23% had been admitted to hospital overnight due to their migraine., with an average length of stay of 2.6 nights.

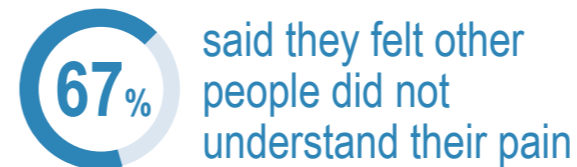


The personal impact

More difficult to quantify is the **emotional burden of migraine**, and isolation it can cause. This section of the survey allowed participants choose the statements that most applied to them and their experience of migraine – this was **shown to be overwhelmingly negative.**

What is the emotional burden of migraine?

When asked how migraine makes them feel, participants gave overwhelmingly negative responses. Over two-thirds (67%) said they felt other people did not understand their pain, and 63% admitted they feel guilty for letting family and/or friends down when they are unable to keep their commitments. Significantly, 59% said they felt their migraine attacks dictate their lives. Participants also commented that it makes them feel “helpless” (49%), “depressed” (45%), “less confident” (35%) or that they are “not normal” (36%). Having to rely on others was an issue for 29% of respondents, while 28% admitted they feel as if others are judging them.



When it came to positive feelings, far fewer participants agreed with the statements provided. Although 41% said they had learned to live with their migraine, just 18% acknowledged they feel responsible for their migraine, and 15% said it had made them stronger. Just 4% agreed they felt in control of their migraine attacks.

The broad-ranging impact of migraine on a person’s personal wellbeing became even clearer with further questioning. A large majority (88%) of respondents said they suffered with sleeping difficulties due to their migraine. When asked how fearful they were of their next migraine attack, 16% reported feeling “extremely fearful” while 24% said they were “very fearful”. Just 11% said they were not fearful at all.

In addition, the isolating nature of migraine was evident, with 89% saying they spend long periods in darkness/in isolation. The average number of hours



spent in darkness in the past month for the survey participants was a staggering 31.8 hours.

How is your quality of life? What is the functional burden of your migraine?

Participants were asked to rate the severity of their pain on a scale of 0-10. The average was seen to be 7.9, with 26% saying they rated it at 10, 13% at 9, and 23% at 8, respectively.

For the vast majority, their migraine had a significant impact on their quality of life and day-to-day routines. Over a quarter (27%) said migraine “constantly interfered” with their daily activities, 44% said it interfered a lot, and 20% said it interfered somewhat. Again, more than a quarter (26%) said they always had to stop their daily activities and rest when an attack came on, and 32% admitted stopping “a lot”. Worryingly a large proportion of the respondents reported not having sufficient energy to complete their daily living or felt fatigued – 23% said they “didn’t have any energy”, 40% said they “often didn’t have” energy and 30% said they had “almost enough”. Frustration was a major issue for respondents, with 31% admitting they are always frustrated by their migraine and a further 37% saying there are often frustrated. Hopelessness and/or helplessness affected 18% of those surveyed “always”, and a 34% admitted having these feelings “often”. Almost all patients – 94% - said they had to cancel plans due to their migraine.

Relationships with family and friend were also significantly impacted by an individual’s migraine and more than three-quarters (77%) said this was their own personal experience. In addition, 94% said their migraine has impacted their social life and activities.

How much support is needed on a daily basis?

People with migraine need substantial additional support from family, friends, and others. Help with everyday tasks was required by 73% of respondents, and of these, an average of 15.3 days help was needed in the past three months. Respondents said this help related to the physical aspects (87%), medical aspects (48%), or emotional aspects (77%) of migraine.

Patient Story

Rowan Maher



I developed a headache just before Halloween 2012. The symptoms included vertigo, nausea and feelings of pressure in my head. My vision was impacted. It was not an occasional or frequent headache, it was permanent, and while it was not always severe, it was always there.

I started to miss increasing amounts of school, not ideal for a sixth year student. My neurologist ran tests and, suspecting it might be migraine based on the strong family history of migraine, started treatment with preventative medication. Whilst some symptoms improved, others became worse; I had to drop out of school completely and my father became my full-time carer. I did my Leaving Cert, however, and while I secured a college place studying Creative Digital Media, unfortunately I was only able to attend for a couple of years and didn't finish the course.

At an MAI information event, we talked to specialists who felt it was clear that I was suffering from migraine. As a result I was able to get an urgent referral to the Headache Clinic at Beaumont Hospital. Over the following few years the staff at the clinic worked closely with me adjusting my medication in the hopes of keeping on

top of ever more severe symptoms.

The easiest way to describe my every waking moment is that my brain is similar to a computer which is overloaded with too much data.

“Light, sound, touch, a busy environment, food; all cause severe discomfort and often increase my pain. I find it hard to think or speak coherently.”

My type of migraine is known as new daily persistent headache, a headache which does not come and go, but arrives and never leaves. I am lucky that my pain tolerance levels are high but it is a constant struggle to keep going, try to function and appear as normal as possible in order to make it through another day. At this point medications are not working.

As with many migraine sufferers the impact is not limited to me alone. My friends rarely see me, as I suffer with an invisible neurological condition they do their best, but find it hard to fully understand.



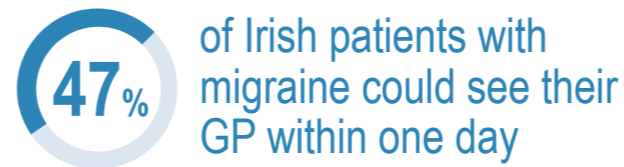
Discussion

While this survey was a global endeavour, the Irish results serve to illustrate the far-reaching impact of migraine, at both a personal and societal level.

The results indicated that 47% of Irish patients could see their GP within one day, while 7% of Irish patients waited 2-3 weeks to see their GP.

The results show that a high percentage of Irish sufferers are then referred on to a specialist or neurologist. Just 44% of Irish patients said their GP is primarily responsible for managing their migraine, while 28% said their neurologist is. Furthermore, 31% of Irish

full-time education; indeed, 77% of chronic sufferers are under the age of 50. The survey findings amply illustrate the sustained nature of migraine attacks, and the resulting impact on everyday activities and work, as well as relationships with family and friends. The survey findings show that support and recognition from employers is often poor amongst this group. Migraine strikes at a time when people are at the busiest and most stressful period of their lives in terms of career, financial and familial pressures. The economic and social impact of the disease is immense.¹⁷

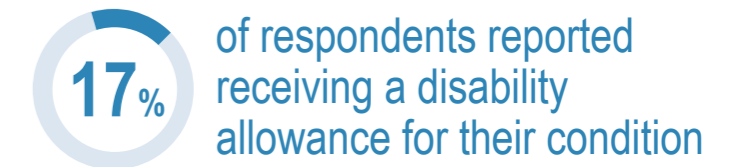


respondents had visited the emergency department in the past 12 months.

Taken together, these findings suggest that chronic migraine sufferers could be better managed within the primary care setting in Ireland. Yet this is unsurprising – Irish GPs receive a relatively small amount of training in headache at undergraduate level.¹⁴ Further training will only take place if they have a personal interest in the area and choose to undertake further professional development in migraine and headache. The MAI provides some training in headache and migraine for GPs in an effort to address this gap, but a concerted effort to substantially improve neurology and specifically migraine/headache training within the national GP schemes could be made.

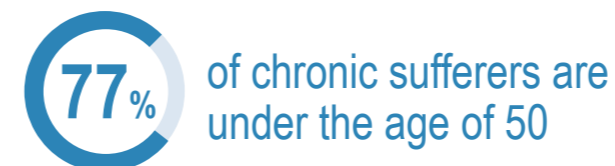
Neurology is historically an underfunded area within the HSE, and migraine does not occupy a place of priority within neurology services.¹⁵ This is despite the fact the WHO now categorises headache disorders (mostly migraine) was the second most common cause of disability.¹⁶ The demographics of migraine show that, unlike some other long-term conditions such as heart disease, diabetes and cancer, the majority of chronic migraine sufferers are either in employment or

Yet just 17% of respondents reported receiving a disability allowance for their condition. This is a relatively low percentage considering the major impact the condition has on a person's social and working lives as represented in the survey results. A distinct gap between sick days and paid sick leave was also highlighted within the data.



The findings also highlight how, for many sufferers, their migraine is accompanied by other chronic conditions. The results of the survey indicate 59% of respondents also suffer from either anxiety or depression. Given that sufferers say they spend an average of 31.8 hours a month in isolation or darkness, an integrated pathway of care with the required ancillary services would be helpful to ensuring migraine sufferers receive the appropriate clinical support. Yet only 9% of respondents had seen a psychologist in the past six months. Psychological supports and patient education are key areas that need to be considered.

The Headache Pathway, which is an integrated programme of care, was developed in partnership with the MAI and forms part of the HSE Clinical Care Programme for Neurology. Launched in 2016, it envisions that the majority of migraine sufferers would be treated in the primary care setting with improved educational opportunities for GPs and practice nurses to enable them








59% of respondents also suffer from either anxiety or depression

to treat the majority of cases in their practices. Within primary and secondary care settings, the emphasis should be on a multi-disciplinary approach with medical options, physiotherapy options and psychological supports. Heretofore, however, there has been no financial commitment with respect to implementing the pathway and none of the recommendations have been implemented to date. The findings of this survey underscore the critical importance of the Headache pathway being rolled out.



Observations:

-  The Headache Pathway should be appropriately funded, resourced and implemented in a timely fashion.
-  Widespread acceptance of migraine as a disabling condition, ensuring sufferers receive adequate social welfare, disability, and sick leave payments would be welcome.
-  A review of medical education pertaining to migraine and headache both at medical undergraduate level and within the GP training schemes may be beneficial.
-  The mental health impact of migraine should receive special attention.
-  Public awareness and recognition of migraine must be improved, to ensure that sufferers get the maximum support they need from their employers and wider social networks.

References:

1. The Global Burden of Headache. *Semin Neurol.* 2018 Apr;38(2):182-190. doi: 10.1055/s-0038-1646946. Epub 2018 May 23.
2. World Health Organisation Headache Factsheet (Accessed Feb 2019) <https://www.who.int/en/news-room/fact-sheets/detail/headache-disorders>
3. Migraine ICHD-3 Classification Criteria (<https://www.ichd-3.org/1-migraine/>)
4. Migraine with Aura ICHD-3 Classification Criteria (<https://www.ichd-3.org/1-migraine/1-2-migraine-with-aura/>)
5. Migraine without Aura ICHD-3 Classification Criteria <https://www.ichd-3.org/1-migraine/1-1-migraine-without-aura/>
6. The family impact of migraine: population-based studies in the USA and UK. *Cephalalgia.* 2003 Jul;23(6):429-40.
7. Employment and work impact of chronic migraine and episodic migraine. *J Occup Environ Med.* 2010 Jan;52(1):8-14. doi: 10.1097/JOM.0b013e3181c1dc56.
8. Condon D. Big jump in neurology waiting list, 2014. Available at: www.irishhealth.com/article.html?id=24245 (accessed 23 February 2018).
9. Becker WJ. The Diagnosis and Management of Chronic Migraine in Primary Care. *Headache.* 2017;57:1471-81.
10. Clark M, Schwedt TJ, Tepper SJ, Harris N, Martin S, Sapra S, Shah N. Patient satisfaction with prophylactic migraine medications. Poster presented at the 59th Annual Scientific Meeting American Headache Society; June 2017. Boston, MA. [abstract] *Headache.* 2017 Jun; 57(Suppl S3):133.
11. Dueland AN, Cabelli ST. The impact of migraine on psychological well-being of young women and their communication with physicians about migraine: a multinational study. *Curr Med Res Opin.* 2005 Aug;21(8):1297-305.
12. <https://www.hse.ie/eng/about/who/cspd/ncps/neurology/>
13. <https://www.migraine.ie/>
14. ICGP Curriculum available at <https://www.icgp.ie>
15. Neurology Clinical Programme available at <https://www.hse.ie>
16. Global Burden of Disease Study 2017, p.13.
17. Linde M, Gustavsson et al. (2012) The Cost of Headache Disorders in Europe: the Eurolight Project. *European Journal of Neurology*, 19(5)703-711.

Photography: All photos are posed by models.

