# MIGRAINES AND MENTAL HEALTH IN WOMEN: ADDRESSING THE CHALLENGE

A JOINT PROJECT BETWEEN GAMIAN - EUROPE AND THE EUROPEAN MIGRAINE AND HEADACHE ALLIANCE (EMHA)

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# **EXECUTIVE SUMMARY**

In a collaboration between GAMIAN-Europe and the European Migraine and Headache Alliance (EMHA), this report seeks to highlight the comorbidity between women affected by severe migraine attacks and mental health conditions. Over 15% percent of the European population experience migraines, with women being estimated to be three to four times more likely to have migraine attacks than men. Comorbid migraines and mental health condition are also highly prevalent.

#### The project aimed to:

- Explore and raise awareness of the link between migraines and mental health in individuals, in particular women and those who identify as women,
- Understand the gender-specific challenges of this comorbidity and its overall impacts on women's quality of life,
- · Explore current care and treatment experiences,
- Develop a set of recommendations to be put forward to governments and other stakeholders, to advocate for better care of women affected by this co-morbidity.

A survey was carried out, along with a workshop, to understand women's experiences, impact and treatment of migraines and mental health. The key findings from 259 women responding to the survey included:

- 77% with a diagnosed mental health condition, mainly depression and anxiety
- 76% were aware of their triggers for migraine attacks, including flashing or bright lights, stress, noise and sounds, which also became a source of anxiety
- · 25% reported their depression or anxiety was connected to their migraine attacks
- Comorbid migraines and a mental health condition was debilitating for women and difficult to manage, impacting negatively day-to-day tasks, social life, employment and caring responsibilities
- 90% took prescribed and/or over-the-counter treatments for migraine attacks, and 30% took antidepressants and/or received psychological therapy for their mental health
- 83% made lifestyle changes to avoid their triggers for migraine attacks, and 45% used prevention treatment
- 48% of women were in touch with a neurologist for their migraines and 16% were in contact with a mental health professional
- 38% appeared satisfied or very satisfied with their treatment for migraines, while 10% were not satisfied or not satisfied at all - noting ineffective treatments and their side effects
- 37% reported that their healthcare professional(s) treated their migraine attacks and mental health condition separately
- Women often encountered difficulties accessing health services, and emphasised the importance of a holistic approach to treatment

Women pointed to the many challenges they experienced with migraine attacks and a mental health condition. Persistent migraine attacks led to depression and anxiety for some, and avoiding certain triggers meant isolating themselves from friends. The negative impact of this comorbid condition on women's lives was considerable, rendering many unable to do anything for days.

Finding the right treatment and receiving the right support from healthcare professionals was not easy, and was exacerbated by the long wait times and a lack of joint working between neurological and mental health services which added to women's stress and anxiety. Many women felt their symptoms were not taken seriously.

Two key improvements to health services included better integrated working between relevant departments, and improved training for health professionals to gain a better understanding of this comorbid condition and its treatment.



# BACKGROUND AND INTRODUCTION

This report represents an important collaboration between GAMIAN-Europe and the European Migraine and Headache Alliance (EMHA). It seeks primarily to raise awareness of the comorbidity between women affected by severe migraine attacks and a mental health condition; an area relatively underexplored in research and policy despite its high occurrence.

Migraine is a neurological condition that often causes strong headaches. These headaches can come and go and are often accompanied by nausea, vomiting, and sensitivity to light. Symptoms of migraine attacks can differ between people and can occur hours or days before migraine attacks, including fatigue, thirst, mood changes, and bloating. Migraines can also come with symptoms of aura, usually affecting vision, speech, smell and touch.

Over 15% of the European population experience migraines, which can severely impact day-to-day functioning. Women are estimated to be three to four times more likely to experience migraines than men. They also experience more severe attacks compared to men.

These gender differences are thought to be partly because of hormonal factors, such as fluctuations in oestrogen and progesterone. Certain hormonal treatments and menopause can lead to a worsening of migraine symptoms in women. Additionally, oestrogen treatment for transgender women can lead to the development of migraines and their symptoms.

While migraines are both frequent and disabling there is also a co-morbid association with mental health conditions. Migraines are strongly associated with depression and anxiety. These mental health conditions also affect more women than men. People who experience migraines are between two to ten times more likely to have a mood disorder (e.g., depression, bipolar disorder) when compared to those who do not. More than 50% of people with migraines also experience an anxiety condition during their lifetime. Mental health conditions are also risk factors for the transition from episodic to chronic migraines.

Some evidence indicates that migraines also impact women's well-being and mental health. Women most often develop their migraine symptoms in their 30s, when they might have to deal with childcare and growing career responsibilities; all of which can create additional stress and impact their mood.

Given the strong link between migraines and mental health conditions, such as mood disorders, and that this comorbidity tends to be higher in women, we explored the challenges and impact of this on their daily lives, the treatment/care received and the strategies used to manage both conditions.

#### **Aims**

The specific aims of the project were to:

- Explore and raise awareness of the link between migraines and mental health in individuals, in particular women and those who identify as women,
- Understand the gender-specific challenges of this comorbidity and its overall impacts on women's quality of life,
- · Explore current care and treatment experiences,
- Develop a set of recommendations to be put forward to governments and other stakeholders, to advocate for better care of women affected by this co-morbidity.

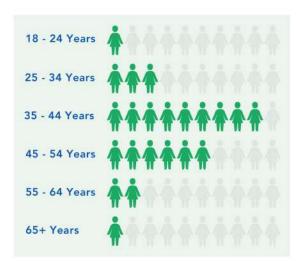
# **METHODS**

The project used two main methods to gather the experiences of women affected by migraine and mental health. This included a survey advertised on the GAMIAN Europe and EMHA's websites and via social media inviting women currently residing in Europe to complete a questionnaire about their comorbidity, its triggers and challenges, strategies used, treatment, and quality of life. A workshop was also convened on 22 November 2022 with five women (from Belgium, Luxembourg, Ireland, Malaysia, and Spain) to understand the triggers and impact of this comorbidity in more detail and what could help improve treatment and care. Key aspects of this discussion have been incorporated within the findings below.

# PROJECT FINDINGS

#### Survey respondents' profile

259 women responded to the survey which ran from December 2022 to January 2023. Most of the women who responded (40%) were aged between 35-44 and 45-54 years (29%). Relatively few were above the age of 55 years. Two women reported being transgender.



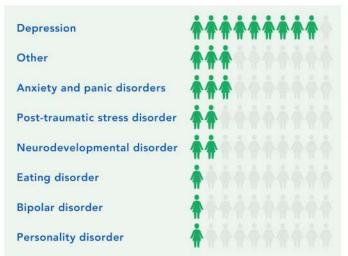
majority of women resided in Norway (86%), although the remainder were from other European countries, including Spain, the UK, Malta, and Belgium. Four women came from countries outside of Europe including India, New Zealand, Tanzania, and the United States. Sixty-one percent were in work, 30% reported being unemployed, and 2% had a disability.

Half of women reported having child dependents under the age of 18 years. A further 12% reported having informal (unpaid) caring responsibilities looking after an older relative, spouse, or adult child with a long-term health condition.



#### Mental health profile

The vast majority of women reported having a specific mental health condition (77%). The range of mental health difficulties was varied, with depression (30%) and anxiety disorders being the most common (16%). Some reported having a neurodevelopmental disorder (7%), such as attention deficit hyperactivity disorder or autism spectrum disorder.





#### Migraine profile and triggers

The majority of women reported having their first migraine attack between the ages of 18 to 24 years. Very few reported this to be in their later years, for example after the age of 45.

Over three-quarters of women (76%) knew their triggers for migraine attacks and reported over 30 different types of triggers. Some were very common, such as bright/flashing lights (34%) and loud noises or sounds (29%). Often triggers were sometimes a combination of different things, including their mental health.

Women noted certain warning signs and patterns that could lead to a migraine attack. For example, spending too much time in front of a computer or other screen. This would lead to a headache, increasing their sensitivity to light. Even taking painkillers at this early stage would not necessarily prevent a full-blown migraine attack. These headaches and attacks occurred 2-3 times a week for some women.

Bright/flashing light	35%	
Noise and sounds	29%	
Stress	22%	
Smells/perfume	12%	
Lack of sleep/ rest or relaxation	11%	

#### Connection with mental health

A fifth of women reported that their mental health (20%), mainly depression or anxiety was connected to their migraine attacks. Half of the women (50%) reported their migraine attacks to be made worse by their mental health condition. For some their mental health was a trigger, for others, it was an outcome; where their migraine attacks led them to feel more depressed or anxious.



My first symptoms were like having a stroke...After this, I was so afraid of getting attacks I developed anxiety without knowing it was that. (R155, aged 35-44, anxiety and panic disorder, Norway).

#### Impact on daily life

The negative impact of having migraine attacks and a mental health condition was debilitating for women physically and difficult to manage, often with no respite in the pain.



My first symptoms were like having a stroke...After this, I was so afraid of getting attacks I developed anxiety without knowing it was that. (R155, aged 35-44, anxiety and panic disorder, Norway).

Some women reported having to minimise or stop entirely the things they did day to day, limiting this to essential tasks.



Having a migraine (depending on the severity) makes it more difficult to participate in anything beyond what is necessary - children, work, and basic running of the household. I would do everything possible to get to a dark quiet environment quickly. (R1, aged 45-54, no MH condition, Belgium)

Often women avoided any social or leisure activities during a migraine attack, including taking any exercise. Fatigue and tiredness were major issues too in terms of impact.



It's a huge effort for me to go on with work and daily chores. I'm tired all the time. I have no social life and don't exercise. I have a poor quality of life. (R3, aged 45-54, no MH condition, Spain)



Migraine attacks make everything harder and even prevented me from participating in activities with family and friends and even challenging myself professionally.' (R20, aged 35-44, neurodevelopment disorder, UK)

The unpredictable nature of migraine attacks and how long they might last made it difficult for some women to plan activities. In preventing migraine attacks many women avoided doing many different and important things.

The impact of migraine attacks affected those in paid employment, their career development, and in maintaining friendships/relationships. This was considerable.



I struggle to make plans, fearful of being too far from home and having an attack. A lot of time I'm in trouble for being sick at work. I've had to use all my annual leave as sick days, and I've lost friends and relationships. (R21, aged 25-34, neurodevelopment disorder, UK)



The fear of triggering a migraine attack resulted in many women, not just avoiding certain activities but also having to lead a restrictive and isolated life, both physically and psychologically, usually worrying about when the next migraine attack would occur.



I constantly worry about the next [migraine attack] and how serious will it be... (R67, aged 45-54, bipolar disorder, Norway)

This added to existing challenges when combined with a mental health condition. Reports of feeling down, low self-esteem, and lack of confidence were common.



Depression makes me feel worthless and the migraines exhaust me. (R57, aged 45-54, depression, Norway)



During and after migraine attacks, I will typically question my abilities as a partner, parent, colleague, and employee. [I get thel feeling of low self-esteem helplessness, uselessness, being a burden' (R179, aged 35-44, no formal MH condition, Norway)

Because typically migraine attacks affected women's ability to perform their work roles regularly and effectively, the economic impact was also felt by many. Several women reported not being able to work anymore, or having to only work part-time. One young woman reported being on long-term sick leave.

The pain and other symptoms of migraine attacks were also of notable impact preventing any decent quality of life.



I have a full-time job, but haven't been able to work full-time in a long time. (R78, aged 18-24, anxiety disorder, Norway)



I am not living, I'm just here in pain waiting for it to end. (R96, aged 25-34, depression and anxiety disorder, Norway)

The stigma and taboo of having both migraine attacks and a mental health condition were also evident. Some women found people lacked an understanding of what it meant to have migraine attacks.





If I have to go home from work or a study group because of a migraine this is met by doubt, not empathy. People know very little about it, they... won't accept facts and info about the diagnosis. (R159, aged 18-21, no MH condition, Norway)

### FIVE KEY FINDINGS



77% of women diagnosed with a mental health condition



Comorbid severe migraines and mental health problems was debilitating for women



48% visited a neurologist, and 16% saw a mental health professional



10% were dissatisfied with their treatment, noting ineffective medication and their side effects



Women emphasised the importance of treating comorbid migraines and mental health holistically

### **FIVE KEY RECOMMENDATIONS**



For health professionals to better understand the link between chronic migraines and impact on mental health



Greater awareness and education for all to reduce stigma



For health services to better integrate services to treat this comorbid group



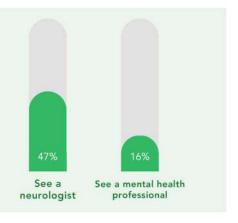
For governments and policymakers to invest in research and health services for better treatment



For employers to provide workplace adjustments and flexible hours

# CONTACT WITH HEALTH SERVICES

Just under half of women (48%) contacted their family doctor about their migraine attacks and mental health. 63% of women were seeing a health specialist; where a total of 48% were seeing a neurologist for their migraines, and 16% were in contact with a mental health professional (a psychiatrist or psychologist).



#### **TREATMENTS**

#### Treatment for migraine attacks and mental health symptoms

Almost all women (90%) took prescribed and/or over-the-counter treatments for migraine attacks. The types of treatments varied enormously, the most common included Botox and beta blockers for prevention treatment, and painkillers and migraine relief medication. Just under a third of women were taking medication for their mental health condition (30%), mostly antidepressants and/or receiving psychological therapy.

#### Treatment alternatives

Treatment alternatives were an important avenue for respondents, with 42% of women using alternative treatments and remedies for their migraine attacks and/or mental health symptoms. These mostly included taking vitamin and/or mineral supplements (23%) (e.g., magnesium and zinc), although 22 other alternative treatments and therapies were also reported, including acupuncture, osteopathy, physiotherapy, and massage.

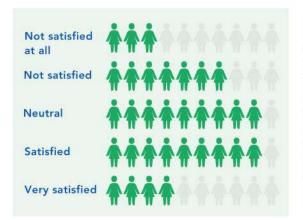


#### Treatment prevention for migraine attacks

Treatment to prevent migraine attacks was also commonly used by 45% of women. The vast majority (83%) also did various things to prevent migraine attacks, many included making lifestyle changes to avoid triggers, such as wearing sunglasses to avoid bright light, no alcohol, reducing stress, taking walks in nature, light exercise, good diet, sticking to regular meals and bedtimes, staying hydrated, and/or resting in a dark room when necessary.

#### Satisfaction and dissatisfaction with migraine treatments

Of the 179 women responding to the question about their treatment satisfaction for migraine attacks, 38% appeared satisfied or very satisfied with it. A smaller percentage were not satisfied or not satisfied at all (10%).



Several reasons were reported for dissatisfaction. treatment Some women highlighted the difficulties of receiving healthcare to investigate their migraine attacks. the pointed treatments to themselves. how thev were ineffective for them, and the side effects they gave.





I was quite scared about the side effects of a daily preventive medication prescribed to me by my neurologist. The main ones were cognitive disturbances, and difficulty focusing and concentrating. For me, these are very important for work. It wasn't worth it and my migraines are not always that severe. (W2, Luxembourg)



I have tried every single medicine on the market. None of which has helped, except triptans. (R100, aged 35-44, eating disorder, Norway)



My life has been way better since last year. I finally have medication that works. (R98, aged 45-54, Neurodevelopmental disorder, Norway)

Some women are cautious about taking certain preventive treatments for migraines, especially if they are not severe.

Or that certain migraine treatments are not suitable for those taking other medications, such as blood thinners, which may lead to adverse side effects.

It appeared common practice to try many different treatments before finding one that worked well.



Other things, such as having a mental health condition also prevented some women from seeking more effective medication.

More than a third of women (37%) reported that their healthcare professional(s) treated their migraine attacks and mental health condition separately.



My attacks have become worse, but my social anxiety keeps me from asking for a more effective medication. (R99, aged 35-44, anxiety and panic disorder)

#### Strategies learned and used

Many women (47%) had discovered or learned things that helped them to manage their migraine attacks and mental health condition. For mental health women reported using psychological programmes that provided tips and tasks to help with managing their mental health. A few strategies included activities that would help with both managing mental health and reducing or preventing migraine attacks. This included reducing stress, regular physical activity for those who can manage this, maintaining a healthy and balanced diet, careful planning with their diary to not overcommit themselves, allowing time for walks, and having a flexible routine.



I have learned that not fighting panic attacks make them easier to handle... and to talk about my anxious feelings so they won't grab a hold of me as easily as they used to. (R99, aged 35-44, anxiety and panic disorder)



I have learned how much stress affects my migraine and depression. My main focus is to get rid of the stress in my life. (R170, aged 35-44, depression)

#### Strategies for reducing migraine attacks and improving mental health



- Reduce stress through breathing exercises and meditation
- Eat a healthy and balanced diet
- Walks outdoors
- Take adequate rest and sleep
- · Have a flexible routine
- Know your triggers
- · Take regular exercise where possible
- · Practice gratitude, acceptance, and staying calm

It was important for some women to find a balance between avoiding triggers for migraine attacks, such as limiting various activities which could lead to poorer mental health.



I try to not avoid things as much as I did before, so my mental health doesn't worsen. (R174, aged 25-34, depression, Norway)



And some used motivational words, distractions, and social media communities/forums to help get through the challenges they experienced.



Take all the good moments in life and remember that it's going to be OK. (R200, aged 25-34, no MH condition, Norway)



Communities on social media help me feel not so alone. I also pick up tips and tricks that have helped me. (R221, aged 25-34, depression, Norway)

#### Treatment improvements

When asked what improvements could be made to their treatment many women were unsure (37%), but 30% were very clear about what could be done. Their suggestions included several themes, including raising awareness and promoting more understanding about this comorbidity, more information about treatment options and effective alternatives, and educating those affected and others about what it means to have migraine attacks and mental health problems.



We need better communication of the issue, awareness raising, and guidance in finding the right doctor. (R14, aged 45-54)



We should educate people about the link between [migraines and mental health] and encourage doctors not to downplay stresses in our lives. Be more mindful. (R20, aged 35-44, neurodevelopmental disorder, UK)

Several women described some of the complications and challenges they experienced when accessing healthcare, what treatments are available, and the treatment process, particularly when having to see different specialists for each condition.



We should always be treating people holistically. That's where our system always falls down. (R19, aged 35-44, depression, UK)

Better follow-up was also considered important, together with an emphasis on more interdisciplinary working between neurologists and psychiatrists/psychologists when seeing patients with this comorbidity. This included better training for health professionals in these fields and finding ways to work together with patients.



They should find solutions together. If the migraine is severe, this is what we need help to her settled first, then the depression that comes with it should also be addressed. (R70, aged 35-44, Norway)

#### Better understanding and awareness

It is important therefore neurologists learn to understand and prioritise mental health in those affected by migraine attacks. Equally important is for mental health professionals to understand the challenges for those with comorbid migraine attacks. It can also be difficult for people to understand any emerging mental health issues because of the stigma associated with it. It starts by asking about these issues and if there is a link between them.





'Just talk to patients about any possible connection between migraine and their mental health. Help them to find a psychologist to see if mental issues are a trigger. It can be hard to realize that you have mental issues. It's easier to say that you have a disorder in your brain called migraine. Mental issues are not as well accepted. (R81, aged 45-54, depression, Norway)

Many women felt their migraine symptoms were not taken seriously, especially by their family doctor.



Migraines are not taken seriously as a medical condition, which needs care. You get prescribed painkillers and that's it. Doctors don't discuss how to manage your triggers or better understand them, they are just dismissed as something emotional. (W1, Malaysia)

Health professionals listening to those with this comorbidity was especially important, and so to adequate follow-up. Often women were simply prescribed medication, sometimes the wrong type, and left to their own devices, without any information or education that could help them to understand what they were experiencing.

Severe migraine attacks are much more than a headache and can be extremely painful. Some women reported how their family doctor (or GP) was often unaware of this and lacked an understanding of neurodevelopmental disorders, such as ADHD and its distinction from mental health conditions.



GPs need to be educated about what chronic migraine is... it is not a "headache". The spiral of hormone cycles, premenstrual symptoms, brain fog, constant pain, and depression. When I have tried to get help in the past, I have been offered antidepressants. I needed help with ADHD, hormone swings, and migraine pain, not an antidepressant. It makes things worse for women like me. (R98, aged 45-54, neurodevelopmental disorder, Norway)

Women also suggested health professionals be aware of how chronic migraines can lead to depression because of the restrictions they can place on what a person can do day-to-day, and not simply prescribe antidepressants to remedy this.





You can get depression from migraines...you can talk to someone, and gain an understanding that you can get very upset by having so many and frequent migraine pains that prevent everyday things (like working and socialising). (R117, aged 45-54, depression, Norway)



The wait time to see a health specialist is another challenge. This is partly because migraine attacks are not always considered urgent or as disabling as other conditions. The implications of being put on a waiting list to see a neurologist can also be anxiety provoking.





A long wait time to see a neurologist adds to anxiety and stress. You are thinking what happens in the meantime, what happens if it's severe, what do I do, where do I go? But if you could go to a dedicated neurologist or migraine clinic at the time of a migraine attack, they can see the impact and observe what's happening in your brain. (W4, Ireland)

Assessments and treatment early on would therefore be beneficial, helping not just to reduce the anxiety associated with not knowing about migraine attacks but also with understanding how it affects the person both physically and psychologically.

# DISCUSSION AND CONCLUSIONS

The survey and workshop provided important insights into women with comorbid migraine attacks and mental health conditions. Many challenges were highlighted. Details of the types of triggers for migraine attacks and the severity of their impact on daily living were significant. For some having the regular persistence of migraine attacks led to depression and anxiety in attempts to avoid certain triggers, which could isolate them from friends and hinder a normal social life. The debilitating impact on work and home life was indisputable. Severe migraine attacks stopped women in their tracks, rendering them unable to do anything for days, impacting negatively on paid work and caring responsibilities.

Finding the right treatment and receiving the right support from healthcare professionals was no easy task for women. This was a difficult journey in itself, often starting with a visit to a family doctor and being prescribed painkillers and then a long wait to see a specialist if referred to one. Any underlying or associated mental health problem was also dealt with using prescription medication, such as antidepressants, without understanding whether this was a trigger or consequence of migraine attacks. Some women eventually found ways to manage their comorbid migraine and mental health conditions, learning strategies they found useful.

The stigma associated with mental health problems added to the challenges experienced by women, where health professionals lacked an understanding of either mental health conditions (e.g. a neurologist) or the impact of severe migraine attacks (e.g. a mental health professional). This hampered attempts to receive the right care and treatment to tackle this comorbid condition effectively and help women achieve a good quality of life.

Many suggestions to improve treatments were made. Better integrated health services, with relevant departments working together, were one. Raising awareness and improved training for health professionals were among others.

Importantly, being listened to and being taken seriously were essential.



# RECOMMENDATIONS

Women participating in the survey and the workshop made a series of important recommendations to improve the experience of comorbid migraine attacks and mental health conditions.

#### For employers to:

- Provide workplace adjustments and flexible working to accommodate those with this
  comorbid condition, allowing sufficient time off or sick leave without negative
  consequences, such as losing their job.
- Have a better understanding of the experience of comorbid migraine attacks and mental health and debilitating this can be.
- Educate and train managers in the workplace about this comorbid condition to allow enough
  flexibility in the days worked and to reduce any stress or pressures associated with heavy
  workloads.

#### For health professionals to:

Provide guidance and training for relevant health professionals - to understand the potential
connection between migraine attacks and mental health, and how these can be both a
trigger or consequence of chronic migraines.

#### For Governments and policymakers to:

- Release more funding and investment in research for better prevention and treatments for comorbid migraines and mental health conditions.
- Ensure better access to healthcare, treatment, treatment alternatives, and prevention medication and activities – to improve the quality and effectiveness of existing healthcare services and experience of them.
- Educate and raise awareness in the general public particularly that migraine attacks are
  more than just a headache, but can be debilitating and restrict people's lives, and that
  mental health conditions should not be stigmatised
- Promote more integrated working between healthcare departments, especially between neurologists and mental health professionals to provide a more holistic/whole-person approach to treatment and care for this group.

#### For women with this comorbid condition to:

- Find ways to understand your comorbid condition and how each may be connected knowing that a mental health condition should not be stigmatised.
- Know your employment rights and help educate your employer to understand the
  adjustments to be made for you and your comorbid condition allowing for flexible working
  arrangements and time off when needed for migraine attacks and mental health symptoms.
- Where appropriate help educate friends, family, and others you come into contact with about your condition and how they can support you to do the best you can.

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