



MIGRAINE WORLD SUMMIT

TRANSCRIPT

INTERVIEWS WITH WORLD-LEADING EXPERTS

HOW TO MANAGE MIGRAINE STIGMA AT WORK

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Introduction (00:05): Most migraine-related productivity loss in the workplace is not due to absences, and that's another fact that shows that people with migraine want to work and come and push through. Eighty-nine percent of migraine-related productivity loss is due to presenteeism. So, people come and are present at work, but they're not as productive as they normally would [be] because of all the symptoms of the disease. So, workplace [headache]-education-[and]-management programs help break down the stigma, increase understanding of the disease, but also help increase diagnosis, access to care, optimize management, and then also increase productivity as a result.

Dean Barclay (00:52): Migraine reaches its peak prevalence in middle age, which is the higher wage earning and productive years of our lives. We could be raising a family, climbing the corporate ladder, only to be derailed at the worst possible time by a spate of migraine attacks. How can we better navigate migraine in the workplace? Should we hide our condition and suffer in silence or tell about it in the hopes of some understanding and accommodation, but also with the risk of stigma from our colleagues? To help us address these questions is Olivia Begasse de Dhaem, a neurologist and headache specialist who advocates for people living and working with migraine. Dr. Begasse de Dhaem, welcome to the Migraine World Summit.

Dr. Begasse de Dhaem (01:50): Thank you. Thank you so much for having me, and more importantly, thank you so much for covering such a crucial topic.

Dean Barclay (01:59): Absolutely. We're excited to have you; we're big fans. So, let's get started. Your advocacy work in the workplace has been very prominent. In fact, you wrote the article that was published in *Harvard Business Review*. We'll come to your article shortly, but let's set the scene for migraine at work. What do people with migraine worry about in their workplace?

Dr. Begasse de Dhaem (02:28): Most common, I think on the day-to-day logistic basis is the unpredictability of the disease. You never know when a migraine attack can hit, which makes it hard to plan and we have some data that this is stressful, and it's not surprising for at least 82% of people working with migraine. Something that — the thing I hear the most commonly in my practice seeing patients is a fear of being fired or having to quit the job because of all of the symptoms of the disease, but also because of the stigma.

Dean Barclay (03:06): Do most people who work with migraine have episodic or chronic migraine?

Dr. Begasse de Dhaem (03:12): So, we have some data about this. Working full time, about 46% of people with low-frequency migraine can work full time, compared to 35% of people with chronic migraine [who] were able to work full time.

Dean Barclay (03:31): Does migraine affect people's quality of work or ability to perform?

Dr. Begasse de Dhaem (03:36): Well, I don't think quality; it's the ability to perform. People are about 50% as effective as they normally would [be] when they work during a migraine attack.

Dean Barclay (03:47): Does it have an equal impact on those working with migraine or does it affect individuals differently?

Dr. Begasse de Dhaem (03:54): It affects people in different ways and even one person can have different symptoms or different presentation of the disease throughout their life. So even within



the same person, migraine is not always the same. Then it also depends on the interaction between the disease and then other factors like the type of job functions they are performing, the work hours, work environment.

Dean Barclay (04:21): That's a great answer. Which brings me to the point, the question of, what types of jobs are trickier for those with migraine?

Dr. Begasse de Dhaem (04:31): Yeah, and I really wish we had more studies about this. Sometimes I feel like I see so many teachers, painters, janitors, some construction workers. So, sometimes it feels like in the clinic we may or may not see trends, but this has not been studied to focus more on the data that we have, that job factors that are associated with a positive impact on migraine-related productivity: so, job satisfaction; sense of autonomy; a migraine-friendly work environment; adaptation in terms of lights, scents, noise. So, these can be positive work factors, and there are negative work factors, such as the workload, unnecessary stress at work, social demands, too. So, [during] a migraine attack, it may be harder to interact with a lot of people during the same day. Then the shift work is also difficult for people with migraine.

Dean Barclay (05:41): So, what types of jobs do you think might be more suitable for those with migraine?

Dr. Begasse de Dhaem (05:48): This question has to be asked because of the current context. I really hope in the future people with migraine can get to the jobs they want. It's kind of crazy to think, I'm not surprised, but I am very upset when I see that 55% of people with migraine have to change their career goals. I do not think that people with migraine should choose the job because of migraine, but currently because of the situation with the disease, with access to treatment, with workplaces, this is the reality.

Dr. Begasse de Dhaem (06:23): But I think a lot has to be changed about that. We need a flexible work environment, as supportive as possible, where hopefully people can make their own hours, or have flexible hours, a sense of autonomy. They work — try to avoid a shift work — and a migraine-friendly work environment as much as possible in terms of the trigger factors or worsening migraine factors. If we want to be allies in the community, we need to try to help support people with migraine get to the jobs they want. But sometimes we can also change things based on what people want.

Dr. Begasse de Dhaem (07:12): For example, if someone is working [at a] nighttime hospital pharmacy as a pharmacist, this is night shift, there's social interaction, bad lighting, this is difficult. But that person may actually be a pharmacist with a day job that is more flexible — for a compounding pharmacy making medications; sometimes we can also work around within the same job. There are some jobs that are very difficult, like for example, welders. There are some jobs [that are] just so hard to adapt the job to the disease. I think that's a little bit harder, but I think following what people want to do and then trying to find something as related as possible, that is more manageable.

Dean Barclay (08:05): OK, thank you. So, let's talk now a little bit about maintaining your reputation and relationships at work. So, do most people hide their migraine at work?

Dr. Begasse de Dhaem (08:18): Yeah, I think so. And I think taking a step back, it's not necessarily that they want to hide it, but migraine is highly stigmatized. It's the most stigmatized of the neurological diseases — stigmatized at work, in language, institutions, in medicine — I



mean it's stigmatized everywhere. So as a result to people, you kind of internalize stigma and self-stigma and that sometimes subconsciously and involuntarily becomes leads to concealment.

Dean Barclay (08:58): What do you think [are] some of the pros and the cons of telling work about migraine?

Dr. Begasse de Dhaem (09:04): So, I think one of the main ways to fight stigma is to be able to disclose and to explain the disease, and to make people realize that people with migraine are not much different from people without migraine, and understand the difficulties of working with migraine, with disclosing the disease, and more education, more understanding; it'll help break down the stigma. So the main pro is to help the greater community, which is really hard to do and very brave to do. And I think we can all understand why some people may or may not feel comfortable disclosing the disease based on the work environment. If it's very toxic and they may feel that they will be fired, obviously this may not be the most optimal decision.

Dr. Begasse de Dhaem (10:01): It also helps I think feeling more validated and more understood. It is just so hard to — even jobs already, right? It's not always easy. Sometimes jobs can get complicated. But to, on top of everything, like wake up with all the different symptoms — migraine is so much more than a headache — push through; push through the commute if people have to commute, and do all this, and not be recognized. At least [provide] the feeling of acknowledgement and recognition for what they do. So I think that's a big pro of disclosing the disease.

Dean Barclay (10:46): Do you have any thoughts on how you should tell work that you have migraine?

Dr. Begasse de Dhaem (10:54): Yeah, I think this is not something that ... I mean depending on the work environment; I'm coming from a place where it's difficult because that's what I hear most about. But when it is difficult, I think you cannot just say, "I'm going to go disclose." I mean you can, but I think it's good to prepare. It is good to prepare to have the most powerful message, but it's also good to prepare because it may or may not be a difficult discussion. Because with migraine, with the stigma, with being used to concealing, hiding the disease, migraine can have a huge emotional impact.

Dr. Begasse de Dhaem (11:31): I think it's good to prepare. So you go talk about your disease, feeling prepared and feeling like you have talked to people; you've got this, they have your back and you're not alone. I think it's good to ask your headache specialist about it; maybe even just talking it out as to how you can start the conversation, getting ideas, brainstorming on what are the symptoms of your disease, what is difficult for you at work, and what would you need at work for things to be better for you. And then if you can talk to allies — allies in the workplace, or friends who have gotten through this, a support group, patient advocacy organization, read stories — to really have a strong point to be able to explain and present data as to: Migraine is a serious disease, [it's the] leading cause of disability in the world, this is how it affects me, what makes it difficult for me in the workplace, and this is what I would need in the workplace.

Dean Barclay (12:43): Great comments on that. So, in terms of tips, do you have any tips for navigating office politics and the people? We know it can't be easy oftentimes.

Dr. Begasse de Dhaem (12:55): No. The question is funny to me because I try to avoid politics as often as I can, so I may not be the best person for office politics; I don't have a poker face. But I



think if finding allies, it's always good. So at least some people who understand; at least some acknowledgment. If possible, getting your supervisor or boss on board is also helpful because they may find ways to adapt your workplace or a supportive effect may trickle down to the rest of the team. And I think in general, be true to yourself, true to your values, true to what feels right. Because the problem of migraine, it comes for a lot of people with guilt and I think the guilt is also from the stigma and then it's always a sense of, "I have to push through, I have to push through." Do you have to push through if there's a late evening work event? [How] do you feel and how does your body feel? If you're not there, people may just be missing you and say the next day, "Oh, we missed you." But I think sometimes it's hard because it's so ingrained into society, but trying to take a step back from that constant pressure, constant stigma, constant guilt ... What do I feel like I want to do, not what I should do and push through.

Dean Barclay (14:27): In the office they're being able to handle those microaggressions in the workplace. Any comments on that?

Dr. Begasse de Dhaem (14:37): I think it also goes back to finding allies because sometimes when it's really hurtful and feels close to home, it may be hard to come up with something to answer. So spreading education, but I think it's important to respond to microaggressions directly when they happen, if you feel comfortable enough. And sometimes I'm wondering do people — taking a step back, do they mean anything bad or do they just not understand? So trying to share facts about the disease, trying to normalize different people have different disease, so that would be beneficial to all of us.

Dr. Begasse de Dhaem (15:23): But I'm not a specialist on microaggression. It's also hard I think, that type of thing. I know it's important to address microaggression, but that's why I feel so strongly about advocacy in the workplace because we can only put so much extra work on people who are dealing with migraine already in the workplace. We need some education for the rest of the people in the workplace to try to reduce how much it happens as much as possible.

Dean Barclay (15:54): So, let's talk about accommodations. What accommodations can we ask for?

Dr. Begasse de Dhaem (16:00): There are some general things and sometimes I think it's good to have a chat with the actual person in question to better understand the work conditions, to adapt to the work conditions, and what's actually logistically possible so it gets approved by HR. But I think in general, a flexible work schedule, or at least daytime, managing the lights, natural light, dimmer light, trying not to use so much bright fluorescent overhead lights. But then some people work outside in the sun, in the noise, with bad air quality, in construction, so then obviously that's not realistic. So, can they have frequent breaks in the cooler, darker room? So we have to also adjust: [with] a sun-free area; adjusting noise; helping with ergonomics; frequent access to breaks, water, restrooms; timeout rooms where people can lie down or be in the dark, or be in a quieter place; make sure people also have time and access to the medications when they need to.

Dean Barclay (17:22): So, in every organization, who would be that appropriate person to speak to? Would it be HR, your immediate supervisor?

Dr. Begasse de Dhaem (17:32): Usually human resources; HR is the best place to go because it's supposed to be confidential and then they can inform you on what forms to fill [out] and what's



possible, not possible. That being said, I think if it's too long to get an answer, or if the answer is not good enough, or you find that you're more comfortable with your supervisor, it also makes sense to first talk to the supervisor and then HR — path of least resistance. Migraine is already limiting enough. Whatever you feel that is easier to get the point across I think works, yes.

Dean Barclay (18:17): Someone in the community has asked: What can you do if you're really afraid to ask for accommodations in the workplace? Do you have any recommendations for that?

Dr. Begasse de Dhaem (18:30): Yes, hopefully that person has access to a headache specialist or healthcare providers who know something about migraine and can discuss this with them. But first of all, sometimes I ask and I write a letter of support or I communicate with HR as a doctor, but without disclosing the disease. So, some people are very afraid of disclosing migraine because of what they've heard or what happened to the co-workers. So oftentimes, even for FMLA [Family and Medical Leave Act] forms, we do not have to necessarily disclose the actual disease. I feel very comfortable writing: "I'm following with so-and-so for a serious neurological disease and that's what's needed."

Dr. Begasse de Dhaem (19:22): So I think we don't always need to say specifics, I don't think — it also goes to the privacy, but that's part of why I was saying it's good to prepare for it and really take a step back: What are my essential job functions and what can be logistically done so I can still do my essential job functions? Or is there some other job within the same company with essential job function that I can do? Because getting reasonable accommodations is a right, but the employer still wants you to be able to do your job if you get those accommodations.

Dr. Begasse de Dhaem (20:02): So, sometimes there's a mismatch. So, talking with your healthcare providers, talking with other people in your field, friends or support groups. Even anonymously — if you don't want to post it, ask someone else to post it or reach out to the group organizer. Can they post it anonymously? Then talk with HR or ask if they can ask your healthcare provider; if they cannot, ask for them to refer you to a social worker to advocate for you and discuss things. But it can be very difficult because then you also need to have HR and the employer to be available and to be willing to help. But this is your right to ask for reasonable accommodations, so they should help.

Dean Barclay (20:55): Well, thank you. Another question was, there's someone in her office, there's someone that wears a certain perfume that triggers her, they've asked them to stop and with no luck. Any tips on how to handle that?

Dr. Begasse de Dhaem (21:17): Yeah, I think it goes back to trying to talk to HR, if not the supervisor, because there's already so many limitations of the disease. It's not up to you to try to pick a fight with co-workers who do not understand the sensitivity and smell sensitivity of migraine. So just gently talking with the co-worker, if you feel comfortable. If it doesn't work, I think taking it to someone external who can resolve this. And that may be resolving this by talking to the other co-worker and finding a solution, or making a policy — a scent-free policy, or fragrance-free policy. Or maybe, sometimes I've also seen people being moved to different location of the office and that can be for smell. Like, I had someone who was close to the kitchen with all the smells, the noise, the lights, and she was so much better when her desk was moved to the exact opposite area, where there were less smells, less noise, more natural light; actually she was close to the window. So, trying to talk with HR, the supervisor, the person in charge to see what solutions they may come up with.



Dean Barclay (22:42): OK. Good, thank you. Those are great pointers. So, in your *Harvard Business Review* article, you referred to several different examples of workplace initiatives to support employees with migraine. What did you find?

Dr. Begasse de Dhaem (23:00): So, there's evidence for workplace headache-education programs, and workplace headache-education-and-management programs, and they increased productivity by cutting down on absences; but also increasing the number of days with increased productivity in the workplace. So, most migraine-related productivity loss in the workplace is not due to absences, and that's another fact that shows that people with migraine want to work and come and push through. Eighty-nine percent of migraine-related productivity loss is due to presenteeism. So, people come and are present at work, but they're not as productive as they normally would [be] because of all the symptoms of the disease.

Dr. Begasse de Dhaem (23:49): So, workplace [headache]-education-[and]-management programs help break down the stigma, increase understanding of the disease, but also help increase diagnosis, access to care, optimize management, and then also increase productivity as a result. It's very important. So, education about headache is meant for the entire workforce, for the entire employees, supervisor, C-suite, all the population. The way to really make an impact is to raise awareness about the disease to help change attitudes toward colleagues who have the disease. In the Fujitsu Headache Project, which is the largest-to-date workplace headache-education-and-management program, 83% of employees who do not have headache said they changed their attitude towards a colleague with headache disease as a result of the program.

Dean Barclay (24:56): Absolutely. So, in a perfect world, what do you wish all employers knew about migraine?

Dr. Begasse de Dhaem (25:05): Migraine is a disease. It's a neurological disease. It's actually a leading cause of disability in the world. People with migraine want to work and there are cost-effective ways to help support people with migraine in the workplace that benefit everyone and increase productivity.

Dean Barclay (25:25): What would you like to see all employers do for their workers with migraine?

Dr. Begasse de Dhaem (25:31): Create a migraine-friendly work environment — not just a physical adaptation, but also in terms of workplace relationships; help support people getting the reasonable work accommodations that they need, and have the right to establish workplace headache-education-and-management programs.

Dean Barclay (25:56): OK, excellent. So, to work or not, do you have a recommendation that people who suffer with migraine, should they work if they want to? If you live with migraine?

Dr. Begasse de Dhaem (26:09): There is work and "work," right? "Work" and "Can you work?" Probably, actually a good number of people with migraine could "work." It's what type of work can they do? Does that match with the professional dreams, professional goals? So I think it's more even than "to work or not to work." A problem oftentimes is that people with migraine can work, but sometimes in my office there's such a mismatch between what people are actually doing and what people did for their studies. And then when you ask more questions, what they intended to do is very different. So people oftentimes can settle for jobs because they have to work, they need to work to support themselves, support their family if they have a



family, to actually keep access to care and medication. But I think this is more complicated than that.

Dr. Begasse de Dhaem (27:14): And then work, but work at what cost? Because people with migraine want to work and when they work, they're very dedicated to their work, they push through, they put work on top of everything else in their life. So, sometimes they push through as a detriment of their well-being, of their health, of their access to care. So, what is the cost of working? I think it's not so much to work or not to work if you want to work, it's how can we make it so people can work in conditions that help people manage the disease and also do something that they want to do?

Dean Barclay (27:55): Thank you so much. Are there any final thoughts you'd like to leave with our audience?

Dr. Begasse de Dhaem (28:01): I think it was probably in one of your questions, but I think about the isolation of migraine. Migraine is terribly isolating and I think it's important to always remind ourselves and everyone that people with migraine are not alone. There's more than 1 billion people in the world [with migraine]. Sometimes when I see people in the clinic, I just want to break down the walls or make group visits because there are people from different stages of life, but sometimes such similar presentation of the disease, and symptoms, and obstacles they're facing. And I think that's why it's important to have education like what you are doing with the Migraine World Summit, but also join a patient advocacy organization or support group to feel less alone because it's a very isolating disease.

Dean Barclay (28:55): So, where can we learn more about what you are doing or follow your work?

Dr. Begasse de Dhaem (29:01): So, what I'm doing, usually what I'm personally doing, I post on social media like LinkedIn or X/Twitter, whatever people call it nowadays. And also, in terms of publication, on the website of the Global Patient Advocacy Coalition — I'm also involved with GPAC. And then to learn more about — so there is a *Harvard Business Review* article, but also the full articles about the Fujitsu Headache Project was published. And I think to see how cost-effective and beneficial workplace headache-education-and-management programs are, I think it's good to share and spread that data.

Dean Barclay (29:50): OK. So those are the resources that you'd like to recommend or are there any other resources that you'd like to offer to our audience?

Dr. Begasse de Dhaem (30:00): I mean there's Migraine at Work — you know this. We talked about it. There's also my favorite, GPAC, and the American Migraine Foundation has good resources, too.

Dean Barclay (30:14): OK. Well, Dr. Begasse de Dhaem, thank you so much. This has been a very enlightening conversation, and I am sure our audience has learned quite a bit about the resources that are available and how to approach their workplace. So, thank you so much. Appreciate you being here.

Dr. Begasse de Dhaem (30:37): Yeah, thank you so much for having me and for covering this topic. As you alluded to, I'm not hard to find if you have questions.