

Dr. Olivia Begasse de Dhaem:

I think we may not prevent chronic migraine on everyone from leaving the workforce, but I do think it has a significant impact on the great majority of people with migraines, because people with migraines want to feel understood, they want to work in a supportive work environment that would actually benefit everyone.

LuAnn Heinen:

That's Dr. Olivia Begasse de Dhaem, a board-certified neurologist who works as a headache specialist at the Hartford HealthCare Headache Center. A leading migraine researcher, Olivia is also the executive editor of the *Pain Medicine Journal*, a member of the International Headache Society and author of the book, *Headache, What Do I Do Now Pain Medicine*. Most recently, her research team published a study focused on a leading cause of presenteeism in the workplace, migraine.

I'm LuAnn Heinen and this is the Business Group on Health podcast, conversations with experts on the most relevant health and well-being issues facing employers.

In this episode, Dr. Begasse de Dhaem and I discuss migraine as a major pain point for an estimated 15% of employees, causing productivity losses that typically go unmeasured. We also explore findings from her study focused on ways to help employees suffering from migraine gain more than 14 days of productivity annually.

Hello, Dr. Begasse de Dhaem. Thank you so much for being here. And may I call you Olivia?

Dr. Olivia Begasse de Dhaem:

Oh yes, for sure. Good morning, LuAnn. Thank you so much for having me.

LuAnn Heinen:

I thought we might start with a patient perspective, if that's okay.

Dr. Olivia Begasse de Dhaem:

Yes, great idea.

LuAnn Heinen:

This was published in the *Times of London* just a few days ago by a member of Parliament of the U.K. named Dehenna Davison. She wrote, in a nutshell, migraine is a debilitating, whole body, neurological condition that can have a wide range of symptoms: head pain, visual aura, nausea, light and sound sensitivity, dizziness, irritability, lack of ability to concentrate and difficulty finding words. The latter, especially unhelpful for a politician. On a bad head day, I'd worry that I'd be judged as weak or unreliable for canceling work commitments, but I also know that if I turned up and pushed through, I wouldn't be firing on even one cylinder, let alone all of them. Then she went on to explain that planning becomes very difficult because you don't know when a migraine attack will strike. And then in a resignation letter to the Prime Minister, Rishi Sunak, she said chronic migraine has made it impossible to do her job. How do you react to this?

Dr. Olivia Begasse de Dhaem:

I was really touched when I saw that article. Really touched by a powerful story that is unfortunately the story of many. The general prevalence of migraine in the U.S. alone is 16%. Migraine affects more than 1 billion people in the world, and yet a lot of people never get to hear the firsthand experience on the significant impact this neurological disease has on people's work and work life. I'm really happy that she so beautifully and openly shared a story on all the symptoms of the disease. At the same time, I'm so grateful to be here with you today. I'm grateful for any opportunity to raise awareness on this, because things have to change. We cannot have people have to leave their job function because of migraine. We need to be able to change workplaces to support people with migraines, to keep them in the workplace.

LuAnn Heinen:

Now, isn't this kind of an extreme example having to leave her job? I think one of the confusing things is there's such a broad range of symptoms and there are severe and chronic migraine and then there's more episodic. Is that right?

Dr. Olivia Begasse de Dhaem:

Yes, there's definitely a spectrum, but migraine directly impacts people's professional life for 80% of people with migraine. So there is a spectrum. Having to leave a job may or may not be extreme because a lot of time people with migraine change jobs or have to adapt in that job. In the migraine impact report, 55% of people with migraine reported that they had to change their career goal. So people may not leave that job directly, but people may need to work in a different way, adapt their job, change their goal. 39% of people with migraine have to miss work opportunities, promotions, additional earning potential. Migraine impacts a lot of people's professional lives.

LuAnn Heinen:

Yes, more than half changing their career goals. That's really significant. Well, how typical is Dehenna Davison? She's a 30-year-old female. Is this a common demographic for migraine?

Dr. Olivia Begasse de Dhaem:

Yes, migraine is common, but migraine peaks during people's most productive years of their lives. It has a huge impact on people productivity. The general population prevalence is about 16%, but it's 30% for women in the thirties, so definitely she's within the demographic of the highest prevalence. Then I don't know so much about being a minister, obviously, but the unpredictability of that attack, the symptoms of migraine, make it very difficult to attend work meetings, social events to give speeches. I can see how her job was very difficult to do with chronic migraine.

LuAnn Heinen:

Yes, it's sad. 30 years old and a rising star in the conservative party of Britain. Yes. Why have we been slow to recognize migraine as a disease?

Dr. Olivia Begasse de Dhaem:

Yes, because it seems invisible to a lot of people for a lot of different reasons. First, there's no specific overt symptom. You cannot just see someone and guess from seeing them that they have a migraine. Migraine is also extremely isolating, because when people have a migraine attack, all they want to do is to be left alone, stay in a dark room with as little noise and smell as possible. People may not actually see people during a full-blown migraine attack. Then in the workplace, most of migraine-related productivity loss is due to presentism. People show up to work, they push through, so people may not pick up that they're not productive as they normally would because of all the symptoms of migraine. For employers too, migraine is mostly underdiagnosed and undermanaged. At an IT company in Asia, 72% of people screened positive for migraine that never consulted for migraine. And looking at commercial insurance, health care book of businesses, the claim-based prevalence of headaches and migraine is much lower than the actual prevalence in the population. Then there's a lot of stigma against the disease too.

LuAnn Heinen:

They are not showing up in claims data, they are not showing up in ERs and physician offices so much, and then they're home trying to feel better in a dark room. *The Atlantic* recently published an article by another migraine sufferer titled, *It's the Best Time in History to Have a Migraine*, followed by the tagline, "So why doesn't it feel that way?" I gather there are more options for treatment now with fewer side effects, yet no magic bullet. Can you give an overview of drug and non-drug treatments?

Dr. Olivia Begasse de Dhaem:

Yes, so everyone with migraine needs to have access to acute treatment, so that's treatment people take as needed during a migraine attack to try to return to function, decrease severity, intensity, duration of the

attack. Usually, we try to give people different acute treatment options based on the severity of the attack, the timing and the circumstances. If someone is at work, they may want medication with least possible side effects that enables them to return to function, but if people are at home, they may want to try a medication that may have most side effect but try to kill the migraine attack. Then for people who have disabling migraine attacks, this preventive treatment, so treatment that are taken on a regular basis to decrease the frequency, severity, duration of the disease. Kind of recently, I mean starting in 2018, we have had more migraine-specific pharmacological treatment on the market and that's positive to help people with migraine in terms of treatment, but it also shows this is a disease. It's crazy, I still have to say that, but we have talked about it how it is underrecognized. We are understanding more and more about the disease of migraine on its pathophysiology, and because of this increase in understanding, there has been new migraine-specific treatment people can take.

LuAnn Heinen:

Olivia, how long does a typical migraine attack take, including any pre and post symptoms?

Dr. Olivia Begasse de Dhaem:

A migraine attack can actually be very long. It can last several days, like three or four days for some people. There's three to four phases of a migraine attack. About a third of people, phase one that can last up to two days and has a lot of symptoms such as fatigue, repetitive yawning, difficulty concentrating, mood changes, increased urination, food cravings, sensitivity to lights, sounds and neck stiffness. Then phase two, about a third of people at phase two, and that's transient neurological symptoms. The most common one is vision changes with shiny scintillating spots in the vision. And then the third phase is the head pain phase, the most commonly known one with severe throbbing head pain with light noise sensitivity, nausea, vomiting for some people. And the last phase that can happen in about two-thirds of people and last up to two days is what is commonly referred by some people as a migraine hangover. It's a hangover feeling even if people didn't drink any alcohol and people can have fatigue, difficulty concentrating and neck stiffness.

LuAnn Heinen:

What does the provider landscape look like? Where do people currently get headache care and how optimal is that?

Dr. Olivia Begasse de Dhaem:

It's not equal in all the states and all the geographical distribution. We have tried advocacy efforts to try to change that. People are working on it, but also the different professional organizations who are trying to provide increasing education to primary care to make sure everyone who goes to primary care can actually, at least, go through the first step of headache disease diagnosis and management. Usually, most people first go to the primary care provider or family medicine physician and get the first steps of diagnosis and management. Then people can get referred to neurology and then a headache specialist. Usually as a headache specialist, we usually see people who have chronic migraine, who have tried many different medications before getting to us.

LuAnn Heinen:

There are, I think I read, correct me if I'm wrong, 560 headache specialists in the U.S. and 39 million migraine sufferers.

Dr. Olivia Begasse de Dhaem:

There's definitely a gap in the workforce and I think that's why it's also important to try to be creative. Clearly we're not meeting the needs with headache specialist clinics, so can we do programs like workplace education and management programs to help employees in the workplace. And that's also why there's an increasing number of programs to educate the providers or health care professionals that patients first meet when they seek care for headaches.

LuAnn Heinen:

Let's go there and talk about migraine and work. First, is it any better outside the U.S. in terms of care for migraine?

Dr. Olivia Begasse de Dhaem:

No, not really. I mean, it's a huge topic, because every country is different. It's fascinating, but even in the U.S. we have strict criteria for certified headache specialists. Also, countries with a lot of headache specialists if you look at the data, but people can be self-proclaimed headache specialists. In general, no, the time to access and time to getting medication is unfortunately very long for a lot of people.

LuAnn Heinen:

Regarding migraine and work, we know from your work among others that migraine is a leading cause of disability worldwide and a leading cause of presenteeism, meaning people are at work but not fully productive. When we understand it's a disabling condition that reduces productivity significantly, it's hard to understand why migraine isn't something on every company's radar.

Dr. Olivia Begasse de Dhaem:

I think it goes back to what we discussed about it being invisible and about the stigma. Also even, at least for some of the employers I've talked to and programs I've seen, there's a lot of well-being programs, but sometimes not too many disease-specific employee programs.

LuAnn Heinen:

Well there would have to be a lot of disease-specific employee programs to address really the range of chronic conditions that impact employees and their families who work. Let's talk first about the survey data, though. Your *Harvard Business Review* article cited a survey of almost 200,000 employers and found that only 22% thought migraine was a serious enough condition to warrant staying home from work. Let's talk about why that's the case. We've already talked about the claims data that it's not that visible. Some other misconceptions or challenges might be there's a lack of absence data captured by many employers. They just don't know for their exempt or salaried population. They don't know absence and they're not measuring presenteeism.

Dr. Olivia Begasse de Dhaem:

In the U.S. for example, FMLA, some employers don't even ask the specific disease for which or record why FMLA is being asked. Sometimes it's just recorded as brain condition, so people don't know. Then a large proportion of people with migraine do not disclose that absence out of fear, because of all the stigma against migraine.

LuAnn Heinen:

Yes, that it's people have a headache or malingering.

Dr. Olivia Begasse de Dhaem:

In another survey of a U.S. representative sample of people with that, they think that about a third of people with migraine exaggerate the symptoms. They think that people with migraine cause a disease by their own unhealthy behavior and that people with migraine makes things difficult for their coworkers. They use migraine as an excuse. So people with migraine do not feel comfortable disclosing that they have migraine, and that's from the data, but I see it in day-to-day practice that some patients when they ask me to fill forms or write letters, they want me to be as vague as possible and not mention migraine.

LuAnn Heinen:

That's interesting. Well, pivoting to some more positive news. In an effort to increase awareness and understanding of migraine's impact at work, you developed a headache education and evaluation program that was implemented at Fujitsu. You mentioned this work earlier, a Japanese company that provides IT services worldwide and stunningly over 72,000 Fujitsu employees participated.

Dr. Olivia Begasse de Dhaem:

Yes, that was a group effort, not just me, and that came as a succession. There has been in the world several workplace headache education programs and workplace headache education management programs, but the Fujitsu headache project is a first large-scale headache education and management program in the workplace. Fujitsu did a lot of really good things. This came as a second health promotion campaign after the data health promotion campaign on cancer. I think the supervisors and employees were used to participating in health promotion campaigns, because that's a second disease specific one. I know we may need to have a lot of disease-specific head promotion campaigns, but at least targeting things like cancer, cardiovascular disease, headache, chronic pain, I think would go a long way. Then there were headache education modules for all the employees, but also one module that was mandatory for supervisors. They were really a top-down approach involving the supervisors and really good promotion of the program to all the employees through email, newsletter, touch points with supervisors. That education program was offered to all the employees based in Japan. More than 73,000 or 91% completed the education part of the program, which is wonderful, because just educating the entire employee population can help make things better for people with migraines.

LuAnn Heinen:

What would you say was learned from this study?

Dr. Olivia Begasse de Dhaem:

Yes, 73% of people increase the understanding of headache disorders and those who say the program didn't increase their understanding said because they already understood the disease, so highly successful. 83% of people without a headache said they would change the attitude toward colleagues with headache disorders. It's really crucial to have large-scale workplace education to every supervisor and employee. When people with migraine ask what is one thing that would help them, what is one change in the workplace that would help them, the first thing that comes up is raise awareness, increase understanding. We can go a long way by just "implementing workplace headache education programs" and that helps break down stigma, raise awareness, increase understanding, decrease workplace conflict, improve workplace relationships between colleagues, and then improves diagnosis and management, because then the employees who were interested could actually have a virtual visit with a brilliant headache specialist based in Japan. Looking at people with moderate to severe headache who participated in the program, this program increased productivity by 1.2 days of absences and 14 days of presenteeism per employee with moderate to severe headache per year. So it's a study to show positive return on investment. Looking at the Fujitsu headache project, I think it's a no-brainer that such a program is productive for everyone.

LuAnn Heinen:

I kind of love that the first result you cited was that more than 80% of people without headaches changed their attitude and you think that is extremely helpful to those who are struggling with migraine. Then second, you said about 14 days per year of full productivity gained per employee with I think moderate to severe headache and then annual productivity savings. I saw in your paper that that was about \$4,500 per employee, per year. Does that productivity saving take into account cost to implement the program?

Dr. Olivia Begasse de Dhaem:

It's also based on the salary of people. We looked at the salary of people in Japan. That's a productivity gain, to calculate the return on investment. Then we included the cost of the program to Fujitsu.

LuAnn Heinen:

And it was a positive ROI?

Dr. Olivia Begasse de Dhaem:

Yes, 32 fold. Yes.

LuAnn Heinen:  
32 fold, \$32 gained per dollar of investment or yen.

Dr. Olivia Begasse de Dhaem:  
Yes, that's why I usually say a number of days saved then the return on investment, because the salaries and everything is different in every country.

LuAnn Heinen:  
Is it reasonable to think that a program like this could prevent migraine from becoming a disabling condition leading to employee departures, disability claims, medical leaves? I mean, what do you think about that?

Dr. Olivia Begasse de Dhaem:  
Prevent is a big word. I think it's like with a newer migraine specific medication, no matter how hard we try migraine is different for everyone. Then there's still people who have severe chronic migraine despite all the new treatments. I think we may not prevent chronic migraine on everyone from leaving the workforce, but I do think it has a significant impact on the great majority of people with migraine, because people with migraines, they want to feel understood, they want to work in a supportive work environment that would actually benefit everyone because a migraine-friendly work environment is good for everyone. Then when asking in those surveys the sort of thing that came up was a flexible work environment, but if at least people are aware that's actually helping reduce the stigma, and stigma, internalized stigma is independently associated with decreased productivity too. If we break down the stigma, you would expect that it helps increase productivity.

LuAnn Heinen:  
Yes, good point. Can you elaborate on the migraine-friendly work environment, both physical environment and you've already touched on the social environment, but anything we haven't discussed there?

Dr. Olivia Begasse de Dhaem:  
Yes, so positive factors associated with migraine-related productivity is supportive work environment. We mentioned sense of autonomy, job satisfaction and physical adaptation. In terms of lighting, try to avoid the bright fluorescent overhead lights, but try more natural lighting, a sun-free area, quiet areas, access to water and restroom, good air quality, good ergonomic setup while working, and then try to avoid the negative factors of really high workload, unnecessary stress in the work environment. Shift work is really difficult for people with migraine. Then the number of social interactions during the day; interacting with more than 10 people during the day when you have a migraine attack is really difficult. Sometimes just having the flexibility of on one day of a migraine attack, trying to work on certain tasks of your job that are less difficult, and then savings or social interaction for a day when people feel better.

LuAnn Heinen:  
What about migraine triggers? Do they really exist? I know that's a little bit controversial.

Dr. Olivia Begasse de Dhaem:  
A migraine attack has different phases. The first phase of the migraine attack, we call it the prodrome. Before the head pain phase, people can have different symptoms, which we call the prodrome, but people can have food cravings. For example, people crave chocolate and it's not that chocolate triggers the migraine attack. The migraine attack started and made people crave chocolate. It's a little bit tricky sometimes to differentiate triggers versus prodrome as some of the workplace factors triggers or worsening factors of the migraine. I try to not get too stuck on triggers, because sometimes we don't know. It's extremely hard to also pinpoint triggers because migraine is a disease that makes your brain hypersensitive to things. Things build up and then reach the threshold, but sometimes it's not clear whether it's the weather change, plus hormone variations, plus lighting of the environment. It is just so hard to pinpoint. Migraine is already such a difficult disease to deal with. I don't want to increase stress of people trying to keep these very intense diaries to pinpoint those specific triggers.

LuAnn Heinen:

Yes, hard to predict. The impact of what barometric pressure and hormones and the construction pounding next door. It's hard to sort it all out. How else can employers support? We've talked about manager and peer education and awareness and then on the benefits and coverage front, are there any thoughts or recommendations there?

Dr. Olivia Begasse de Dhaem:

Yes, so some places have ergonomics help or ergonomics evaluation. I think that helps with migraine, but that helps with a lot of other chronic pain. From a benefit standpoint, making sure that the migraine medications on the formulary is covered by the health insurance plan of the employer.

LuAnn Heinen:

What gives you optimism about the future?

Dr. Olivia Begasse de Dhaem:

Optimism is that our understanding of the pathophysiology of migraine keeps increasing, so that will lead to more treatment. The optimism too is that there was just the International Headache Congress in Seoul where a large number of headache specialists from all over the world met and there's really a recognition from the International Headache Society and its members that we need to continue to work together and try to make a positive change in the world. It's not just "focusing on the U.S." but really collaborating across the globe and learning what ideas are working in one country versus another country and trying to advance as a team to improve education, access to care, and decrease stigma all around the world. The increase in international collaboration makes me really optimistic too.

LuAnn Heinen:

Can you give us just a little bit of information about your background? You were born in Belgium, educated in France, then what?

Dr. Olivia Begasse de Dhaem:

Yes, then I moved to the U.S. for college, studied mathematics and biology and then went to medical school, then neurology residency, and then the headache fellowship. There is actual medical training to become a headache specialist. I love seeing patients and being in the clinic, but I really think that we have to think outside of the walls of the clinic to make sure we find people with headache diseases where they are to make sure the largest number of people get diagnosed and get access to care and treatment.

LuAnn Heinen:

100%. I love that philosophy, to bring health care to the people.

Dr. Olivia Begasse de Dhaem:

In the U.S. the idea was trying to focus on the workplaces and we'll try to do more programs for schools. But then when I was talking with headache specialists from Africa, a lot of people in Africa don't even see a doctor for the neurological diseases including migraines, so how can we go and do outreach to community workers, to different people in the community, to try to educate about headache diseases, because clearly if we only in a sense treat people who are able to show up to the headache specialist clinic, we are missing a lot of people.

LuAnn Heinen:

I appreciate your vision, your commitment and enthusiasm for this subject. Thank you so much.

Dr. Olivia Begasse de Dhaem:

Thank you so much for having me.

LuAnn Heinen:

I've been speaking with Dr. Olivia Begasse de Dhaem about how attitudes are evolving to understand migraine as a neurological disorder, along with what employers can do to optimize their physical and social environments to support employees at risk. To find a certified headache specialist near you, visit the American Migraine Foundation's website and use their *Find a Doctor* tool.

I'm LuAnn Heinen and this podcast is produced by Business Group on Health, with Connected Social Media. If you liked the conversation, please rate us and leave a review.