



INTERVIEW TRANSCRIPT

DISCUSSIONS WITH WORLD-LEADING EXPERTS

Navigating U.S. Social Security & Private Disability Options for Migraine

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Introduction (00:04): For many people living with migraine, the disease can take an enormous toll on work, identity, and financial security. At some point, you might find yourself wondering if you can even keep working, or whether disability is the next step. But as many discover, applying for disability is far from simple. It can be a long, stressful, and emotional process. And not everyone who applies is approved, even with severe migraine.

Introduction (cont.) (00:29): Today, we're joined by Stacy Monahan Tucker, a leading disability lawyer. She has helped many people navigate this complex system. She'll help us understand what disability benefits really offer, why they're so hard to access for migraine, and how to make informed choices, whether you decide to apply or not. Stacy Monahan Tucker, welcome to the Migraine World Summit.

Stacy Monahan Tucker (00:50): Hi, thank you for having me.

Kellie Pokrifka (00:52): Before we start this, I just want to address that for a lot of us going through this process or having migraine affect our work in any capacity is an enormously stressful experience, and a lot of us feel very isolated and even ashamed. And if you are feeling that you're the only one going through this, we would not be having this interview. This is so prevalent. I myself have had migraine dictate what I've been doing for work my entire adult life. You are so far from alone. The migraine community is here to support you and have your back as you're going through this.

Kellie Pokrifka (01:27): All right, so let's start. Starting with the basics, what exactly is disability insurance? What does it do and what does it not do?

Stacy Monahan Tucker (01:34): That's a really good question, and disability insurance can mean different things depending on the context. There's Social Security Disability Insurance [SSDI], which most people — if they've worked for any amount of time, including in the past — will be able to access. But it's not automatic. If you haven't worked, if you've only worked for a couple of years, or if you worked sporadically, you might not have built up enough credits to access Social Security.

Stacy Monahan Tucker (02:02): So that's one type of disability, which is what a lot of people think of when they think of disability. If you are employed, especially if you're employed for a larger employer, most employers offer short- and long-term disability as part of your benefits package. A lot of people are not even fully aware of this because when you get hired and you look at your benefits package, most people are focused on their health care, which makes sense. You know that's what you're going to be using.

Stacy Monahan Tucker (02:30): But tucked in there is coverage for short- and long-term disability, which will actually cover a lot more than Social Security does. Social Security has a max amount, depending on how much you make, of up to, I think now it's just over \$4,000 a month. That's the absolute highest for people who were making hundreds of thousands of dollars. For most people who were employed at the time they became disabled, they're able to get usually about 60% of their former salary through disability.

Stacy Monahan Tucker (03:05): So, while not as great as being able to maintain your former salary, that's a lot. For many people, that will be a lot more than the max that Social Security can provide. So I focus on helping people with the insurance they get either through their jobs or that they purchase separately. You can always go and purchase disability insurance and just have it as an individual policy that's linked to you; it's not linked to your job. That's another way of having disability insurance.

Stacy Monahan Tucker (03:35): Some people have both. They have it through work and they buy their own policy for additional peace of mind. I am familiar with Social Security because many of my



clients are dealing with both. And insurance companies actually force you, if you've been disabled for usually more than a year or two, to apply for Social Security because their policies are set up to have it be an offset. Which means that if you get Social Security, they subtract it from what they owe you.

Stacy Monahan Tucker (04:04): So they want you to apply for Social Security because for them, it's a win-win. If you're approved, they deduct it from what they owe you. If you're not approved, they point to that as evidence that you're not disabled and use it to terminate your claim. So I am familiar with Social Security because it plays in a lot with what I do. But to be clear, it's not what I specialize in. So I'm happy to answer questions about it and explain how it works and interacts, but I want to be clear, that's not my specific area of expertise.

Kellie Pokrifka (04:35): OK, so to be clear, you can apply for and qualify for both private and —

Stacy Monahan Tucker (04:41): Absolutely.

Kellie Pokrifka (04:42): Am I using the term correctly? Is the private insurance the one you apply for outside of your employer?

Stacy Monahan Tucker (04:48): Yes. It's usually called an individual disability insurance. And you literally contact an insurance broker or an insurance company and you purchase your own policy. And with that, it can be much more flexible: It can be a dollar amount; it can be tied to your income at the time you become disabled; it can be set up a variety of ways. It can include cost of living adjustments each year. And you pay for that privilege.

Stacy Monahan Tucker (05:15): You're paying usually a few thousand dollars a year to have that insurance in case you need it. What you get through your job, usually either you pay nothing or you pay a very small amount each month, like pennies often or a few dollars a month. And it's a benefit that you get through work and it's automatic. And so long as you become disabled before your last day at work, it is available to you.

Stacy Monahan Tucker (05:42): So if you are disabled and, say, you find out you're getting terminated because you're not able to meet the requirements of your job because of your disability, you can still apply for disability. You can make a retroactive claim if you didn't realize at the time that you were disabled when you left work. If you leave work because you just can't do it anymore and later you realize, "I had disability insurance, I didn't even know," you can make a retroactive claim in most states.

Stacy Monahan Tucker (06:12): That's state-specific based on the law, but most states will allow you to make a retroactive claim. So knowing that this is a benefit, just like your health insurance — no one would hesitate to use their health insurance or their vacation time. This is the same thing. And understanding what your benefits are and how to use them is an important part of any job. It's part of your payment package.

Kellie Pokrifka (06:37): With individual insurance plans for disability, is that something that you would have to have got way before you started showing signs?

Stacy Monahan Tucker (06:46): They will look at your medical records for the past several years, and if you've been treating for migraine, they'll still insure you, but they may require that you carve out migraine as something that they are willing to cover. They don't do that with your group disability insurance that you get through your employer.

Stacy Monahan Tucker (07:09): With your employer, if you're a new employee, you could potentially be excluded from making a claim for migraine if you'd been working there for less than a year and if you had treated for migraine in the three months prior to starting the new job. They have a



preexisting condition and limitation in the first year of employment that limits your ability to make a claim for anything you were actively treating for within three months prior.

Stacy Monahan Tucker (07:40): So if you've got a prescription for medication related to your migraine, that could keep you from making a claim in the first 12 months. If you have gone in to see your doctor about migraine, the insurance company will see that in your medical records, and that will be a basis to deny your claim. It only applies for the first 12 months, but it's important to be aware of that.

Kellie Pokrifka (08:07): Is that affected at all, on job applications when we have to mark, “Are you disabled? Do you have any medical conditions?” Does that come into play here at all?

Stacy Monahan Tucker (08:18): It shouldn't, no. And your employers are not allowed to discriminate against you for healthcare conditions. So long as your migraine enables you to fulfill the requirements of your job — what's called the material duties of your job — it should be irrelevant. It's when it starts interfering with that and making it so you can't regularly be there during your work hours, your schedule is too erratic, you're not able to focus or concentrate, or the pain keeps you from participating. That's usually when you get to the point where you want to make sure that your employer knows, see if there's any accommodations that can be reached to allow you to keep doing your job. And if not, that's when you need to talk with your doctor about whether or not applying for disability makes sense in your situation.

Kellie Pokrifka (09:10): And with the year rule, once it's 12 months at that point, and you're suddenly able to be covered for that treatment, is that ever affected if you've asked for accommodations or if you show symptoms to your workplace before those 12 months?

Stacy Monahan Tucker (09:29): Absolutely not. No. The insurance company only cares about any claims you have made. So long as you have not attempted to go out on disability and made a claim with them in particular, it's a nonissue. If you took FMLA [Family and Medical Leave Act] because you were sick and needed to stay at home, or if you went out on short-term disability, you can go on short-term disability within the first year. It's only the long-term disability that has the preexisting condition limitation.

Stacy Monahan Tucker (10:00): So if you went out for six weeks and things got under control and you were able to return to work, and then a year later, your migraine had another flare-up. And this time it didn't resolve and you were out on short-term disability again, and then after short-term disability, long-term disability kicks in. If you'd been working for over a year at that point, you don't have to worry about it.

Kellie Pokrifka (10:28): And with that, with short-term disability and FMLA, how is wage replacement different than job protection?

Stacy Monahan Tucker (10:34): Wage replacement is not required in most states. There are states that offer wage replacement as part of a state program. Job protection has nothing to do with your salary. They may have to protect your job for a period of time, but they don't have to pay you. Many companies do because, again, it's part of their payment package to you. Usually that's set up as short-term disability.

Stacy Monahan Tucker (11:02): And most companies offer short-term disability anywhere from three months to some now go up to a year, and they could be paying anywhere from 70% to 100% of your salary in that time. Every company is different. There's no law that requires them to do anything in particular there. It's a choice that they make, and it's part of your total employment package. So they don't have to do it. They do have to comply with state and federal law in terms of protecting your job.



Stacy Monahan Tucker (11:36): You can't be terminated during the protected period, but they don't have to pay you in the protected period. And outside that protected period, if you're not able to do the requirements of your job, you can be terminated even if you are on disability. Being on disability does not protect your job. They don't have to keep having you employed and providing you benefits if you are disabled. So a lot of people are surprised to learn that, especially because they get their health care through that.

Stacy Monahan Tucker (12:11): And so being terminated involves losing your health care. You can go on COBRA [Continuation of Health Coverage]. If you have a spouse or a partner who's employed, or you're young enough to have a parent and be on your parents' insurance, those are all alternative ways to get coverage. But the next step then, if you are approved for Social Security, you get Medicare coverage. And that's why a lot of people want to also be approved for Social Security, because it will provide them health care.

Kellie Pokrifka (12:39): If you are overwhelmed by all of these potential benefits and you're not really sure how to read into it. And it's not long-term disability — so for FMLA or short-term disability — is going to someone like HR recommended or is that risky? How would someone go through that?

Stacy Monahan Tucker (12:57): HR is supposed to be there to help you, no question about that. HR is familiar with the healthcare benefits provided, because people call and ask about that a lot. HR is often not very familiar with how FMLA works, how short-term disability works, or how long-term disability works, because it doesn't come up as often for them. And what I have found is that they frequently give misinformation, not intentionally. I don't think it's an intentional trying to sabotage you.

Stacy Monahan Tucker (13:28): For example, I had somebody call me just yesterday who works for a large national company. And while out on disability, he was included in a layoff. And his benefits were terminated at the same time. And he called to ask why. And they said, "Oh, well, once you're not employed, you don't qualify for ongoing benefits." That's not true. It says very clearly in the short-term disability plan that if you're disabled at the time your employment ends, those benefits continue.

Stacy Monahan Tucker (14:00): So again, I don't think the person he was talking to was trying to mislead him intentionally. I think she didn't know. And I think that happens more often than people realize. HR individuals only know what they've dealt with and what they've been trained on. If it hasn't come up, they're often as much in the dark as you are. So ask for the original documents, ask for your company's leave of absence plan, ask for your company's short-term disability plan. Ask for it in writing.

Stacy Monahan Tucker (14:34): They're required to give it to you. If you ask for the short-term disability plan — there's a federal statute called ERISA [Employee Retirement Income Security Act] that governs all the benefits you get through work. Basically, it covers your health care, your short and long-term disability, any life insurance you get, any severance, and any 401k plans. It's governed by very specific laws and regulations.

Stacy Monahan Tucker (15:05): If you request a copy of a plan in writing, they have to provide it to you in 30 days or they start incurring fees, penalties of up to \$110 a day. So you are entitled to this information. And a lot of times, people in HR don't know this because they're not ERISA experts. They're not benefits experts. They're more focused on payroll and usually health care. Outside of that, they don't always have a lot of information.

Stacy Monahan Tucker (15:34): So you want to get the actual documents that govern everything so you can look at it yourself and say, "Hey, look at this. This says X and you told me Y." Most of the time, when it's pointed out to them, they'll realize they made a mistake and apologize and move on.



Kellie Pokrifka (15:50): Are there ERISA experts that people can contact? How would they go about doing that?

Stacy Monahan Tucker (15:55): I would be one, yes. There are a lot of attorneys who focus in this area because it is a specific, somewhat niche area. And so, yes, there are absolutely people you can call and contact and ask questions. Most attorneys are happy to do a consultation and answer some questions. And unfortunately, the reason we're very willing to do this is that if you're making a disability claim, sooner or later, the insurance company is going to terminate your benefits. They might deny them outright.

Stacy Monahan Tucker (16:28): Most people don't realize that their insurance — it's an adversarial relationship. We all think of insurance as being there to help you when you need it. The insurance company does not look at it that way. And neither does Social Security, to be fair. This is true for both. It is difficult to get these benefits. And that is intentional. It is an adversarial relationship. They are not there to be your friends. They are there to find reasons to deny your benefits. It's a business model.

Stacy Monahan Tucker (17:00): Obviously, it costs them money to pay these benefits. So they deny most claims and then they wait and see who pushes back. Most people don't push back. Most people, when they're told that they don't qualify, are sick and exhausted and do their best to try to go back to work. Or they quit and they stop working because they don't know better. And unfortunately, under ERISA, you have to appeal a denial within six months or you permanently lose the ability to pursue that claim.

Stacy Monahan Tucker (17:33): And they explain this in the denial letter. But again, most people don't understand that. And if they do, they just send in a letter saying, "You got this wrong. I'm sorry. Maybe you didn't understand. I'm really sick. My doctor says I'm really sick. My doctor completed your form. So please reevaluate and fix your mistake." The insurance company looks at that and says, "You didn't submit any new information." And you're done.

Stacy Monahan Tucker (18:00): After that, the only thing you can do is bring suit against the insurance company or the plan. And that sounds like a nuclear option. But in fact, insurance companies are sued tens of thousands of times a year. Again, it's part of their business model.

Stacy Monahan Tucker (18:18): Once you bring suit, then the insurance company's outside counsel looks at it and usually looks to negotiate a buyout of the benefits, which, depending on your job, your age, what your disability is — assuming it's migraine-related here — and your salary, you can negotiate, sometimes, a very large lump sum payment. And then you're done with the insurance company. If you're able to, you could go back to work the next day. If not, you can hold onto that money and invest it and have some security while you focus on your health issues.

Kelly Pokrifka (18:56): So what do we have to prove to qualify for SSDI?

Stacy Monahan Tucker (19:01): For SSDI, you have to prove that you are disabled from any occupation. That doesn't necessarily mean that a CEO is going to be asked to go work at McDonald's. They do look at your education and your background and your qualifications to determine what your job is and what your disability is.

Stacy Monahan Tucker (19:27): From a health perspective, both Social Security and private disability insurers are usually focused on the idea of whether or not you can sit at a desk. They don't like to look at what I view as the mushier aspects of health. They don't like to look at fatigue. They don't like to look at pain. They don't like to look at the irregularity of your situation — that some days you might be fine, and some days you literally can't get out of bed and have to lie in a dark room all



day. And that maybe you could occasionally answer an email, but even that makes you feel sick for hours. Insurance companies don't like that.

Stacy Monahan Tucker (20:12): When they send your doctor an initial form to fill out — I was actually just looking at Hartford's today because I was helping a client fill it out. It asks how long you can sit, stand, and walk, and it asks if you've had any MRIs or X-rays or any lab work done. That's all it asks. Obviously, that does not necessarily tie in to the symptoms that somebody with migraines or a TBI[traumatic brain injury] will necessarily be experiencing. You don't have back problems. You're not precluded from sitting per se. But you may feel nauseous, you may feel dizzy, you may have to lie down for those reasons.

Stacy Monahan Tucker (20:56): The forms they ask a doctor to fill out don't even give them any space to address that. And that's intentional. That's very intentional. They don't like these claims, and so they try to avoid them. From the get-go, whether it's Social Security or private disability, you're in a situation where your doctor's already having to play with the language to make clear what your disability is.

Stacy Monahan Tucker (21:25): Once you make that claim for Social Security — this is true for Social Security and private disability — you'll sign a bunch of forms. They'll gather all your records, and then after they gather your records, they will often contact your doctors. They'll have their own doctors look at it, and then their own doctors will contact your doctors for what's called a peer review, and they consult. If your doctor doesn't return the call because your doctor's busy and your doctor doesn't get paid for these, the insurance company and Social Security look at it as lack of support for your claim.

Stacy Monahan Tucker (22:06): So that's another hurdle that a lot of people find themselves having to deal with. Their doctors may support their claim and agree that they're disabled, but doctors don't get paid for all of this extra work, and insurance companies know that. And so they require all of these documents, they require all of these phone calls, and if a doctor doesn't respond, they choose to view it as an announcement that your claim is not supported.

Kellie Pokrifka (22:36): That is terrible.

Stacy Monahan Tucker (22:39): It is. It is a big problem, and we all already know that it can be difficult to get in to see our doctors. It can be difficult to get their attention, not because they're not supportive, but because they have a lot on their own plates, and a lot of patients, and a lot of ways they're already trying to support their patients. Asking them to do all of this additional work that they can't bill insurance for and that they are essentially donating their time for can be challenging.

Stacy Monahan Tucker (23:10): And I'm encountering more and more situations where doctors won't fill out forms at all. They just say, "We don't do disability forms." That's Social Security, that's private insurance, that's any insurance. And that leaves you up a creek without a paddle because medical support is the key and primary basis for any disability claim.

Kellie Pokrifka (23:33): So are there just no options at that point for someone whose doctor won't do it?

Stacy Monahan Tucker (23:37): Find a different doctor. I'm finding that Kaiser, for example, many of their doctors there are just instructed — tell them you won't fill out forms. If you're in a Kaiser HMO, that clearly is going to limit your options. If you are able to see a doctor outside that system who is willing, that's a time to move forward with that. If you have a headache specialist who doesn't fill out disability forms, your primary care physician may be willing and able to do it.



Stacy Monahan Tucker (24:14): So again, that's where you have to start getting a little creative. If the doctor who treats your migraine primarily is unwilling or unable according to the rules of their practice to complete disability forms, the next step may be finding a doctor or approaching a doctor you already see and asking them to do it.

Stacy Monahan Tucker (24:34): Naturopaths are fine. Social Security is required to accept them as a medical doctor. Most private insurance contracts say that they will accept any doctor who is acknowledged as a medical professional in the state in which they're practicing. So, so long as your state acknowledges naturopaths as practicing medical physicians, that's not a problem. And naturopaths are usually much more willing to take the time to provide this sort of documentation.

Kellie Pokrifka (25:08): I want to ask again, with the very restrictive forms, how doctors can phrase your limitations to try to set you up better for success with migraine. But also, I've heard about the one-year rule where you have to have continuous symptoms. And so a fluctuating condition like migraine can be difficult with that. Can you put those all together and how someone with migraine could do that?

Stacy Monahan Tucker (25:33): Absolutely. You are correct. All of that can be very challenging. One of the most difficult situations I encounter — people want to work. Their identities are wrapped up in it. Their social lives often are. Obviously, their careers, what they've been working towards. Nobody is looking to sit at home and live off of disability. It's nobody's first choice. So what people often do is push themselves to work as much as they can, often working part-time or seeking accommodations.

Stacy Monahan Tucker (26:08): As you very accurately noted, that same effort can sabotage somebody when they are looking to make a disability claim. Insurance companies offer part-time disability. Social Security does not. Social Security is an all-or-nothing thing. And so it can be difficult to get Social Security if you are not completely disabled from work. You can, for private disability, make an application for part-time disability.

Stacy Monahan Tucker (26:39): I will tell you now that those are challenging because insurance companies, instead of being delighted that you want to be working, ask, "Well, if you can do this for four hours a day, why can't you do this for eight? If you can do this for three days a week, why can't you do it for five? If you can do 30 hours a week, there's really no reason you can't do 40." And it's difficult to provide quantitative support on why you can work 20 or 30 hours, but not 40 hours.

Stacy Monahan Tucker (27:10): Your doctor can completely support that, but insurance companies like data. One of the things that I found very helpful is keeping a headache journal. Your doctors are probably already encouraging you to do this for treatment. It can also be incredibly useful to demonstrate to the doctors at insurance companies why you can't work — demonstrating that in a four-week period, you have 12 days of severe migraines and you cannot be relied on as an employee because you're simply not able to be there on the regular 40-hours-a-week basis that is a material requirement of your job.

Stacy Monahan Tucker (27:57): So tracking that information and being able to give actual data on what you're dealing with every day — maybe you're able to work part of every day, but you're having chronic daily migraines. Let's say it's just in the morning. Let's say you wake up and you've got a terrible migraine almost every day for the first four hours. Then it resolves, but then you're dealing with all of the post-migraine issues: the exhaustion, just feeling like you're beat up and you're just getting over being sick. Yes, you can probably work for a couple hours a day, but you're not going to be able to put in a full-time day. Tracking that and being able to give them that data can help quantify it for them so that they can better understand what you're dealing with. And of course, the nice thing about it is you're also helping your doctor.



Kellie Pokrifka (28:58): I'm going to use a personal example actually just from this week, and I want to know if writing this down would be helpful or if it would be believable to someone who hasn't experienced these levels. I tried to push myself, and I was sitting on extra screen time trying to do work for maybe 10 hours one day. And then on Tuesday of this week, I spent the entire day so overdone. I was vomiting all day. I could not even sit upright, let alone be at a computer. Is that something that we could write down and that could be useful? Or is that something that they're like, "Well, you worked 10 hours. You're fine. You're good to go"?

Stacy Monahan Tucker (29:42): Absolutely. And this comes up in a lot of situations, not just migraines. A lot of disabilities have what's known as post-exertional malaise, where you push yourself beyond what you should and you try because you have something that's important that has to get done, and then you are a disaster for the next day or two. And tracking that and demonstrating it — one of the things we often do when we're helping somebody make a claim or appeal a claim is get testing. Send somebody out for a two-day functional capacity evaluation. The two-day is very deliberate because the first day, people try their best. They push their way through. The second day documents that crash that so many people can experience where they've overdone it, and they're simply physically not able to do what they did before. And again, that provides quantitative evidence to the insurance company that these things are happening. A third-party medical professional has witnessed this and has written up a report about it. Honestly, most doctors won't do this. Usually, you have to go out to a special evaluator who does this.

Stacy Monahan Tucker (30:51): And if you are making a disability claim and it's been denied, the next step is an appeal. One of the reasons — you don't need a lawyer or anybody to help you in making a disability claim. There are people who do it, and it's because they're sick and they're overwhelmed. And to them, it's worth it. To them, it's worth paying somebody to deal with this for them. That is completely valid. And I have clients who do that and I am happy to help. But for a lot of people, they need their disability benefits. They don't want to give any portion of it to an attorney. So you don't need one to make a claim. You really don't. When you do need an attorney is when you're doing the appeal.

Stacy Monahan Tucker (31:35): And that's because most people, when they do an appeal, they just write in a letter saying you got it wrong. And they don't understand that if your appeal is denied, that's it. You're done. The only other option you have is litigation. And under ERISA, the only information a judge is allowed to look at — there's no witnesses in ERISA. There's no discovery in ERISA. All a judge can see is what's in your claim file.

Stacy Monahan Tucker (32:06): So if all you did on your appeal is send in a letter, that's all the judge sees. And depending on where you are in the country and who your employer is, different states have different standards about how a judge looks at it. Some judges are required to give the insurance company the benefit of the doubt if their decision seems like it could be reasonable. Some are allowed to look at it with a fresh eye and just say, "What do *I* think?" It really depends on where you are, who your employer is. There's a lot of nuance to that. But for a judge who's required to give the insurance company the benefit of the doubt, if all you send in is a letter saying, "Hey, you got it wrong," that's, unfortunately — what is a judge going to do with that? The judge is going to say, "You didn't provide evidence." And so the appeal is when you want to get help because a lawyer is going to help you get all that testing in and identify all the information.

Stacy Monahan Tucker (33:13): Also, because if the appeal is denied, the next step is litigation, they're preparing for litigation. Witnesses aren't allowed in the litigation, but you can put in witness statements into the claim file. So you can put in statements from your friends and loved ones and coworkers about how they've seen you not be able to do this. You can put in your own statement about what you've been dealing with. Put in your headache diaries. Put in all your medical records. Put in the outside testing. Put in medical journal articles about what you specifically are dealing with,



because judges aren't doctors. And judges are used to having experts that they can learn from in the course of a litigation. So we put that information in so that they have that opportunity.

Stacy Monahan Tucker (34:03): Because otherwise, it's the insurance company's doctors who have not met you and have never spoken to you claiming, "Oh, there's no reason they can't work full time with this." And your own doctors who do know you and are treating you, the insurance company says, "Oh, well, they're biased." They're biased because they want to help you, ignoring the bias that the insurance company doctors have. And so it can be difficult in a who's who of doctors for a judge to know who's correct. And so providing unbiased medical information can help give them those extra viewpoints that can help them understand what's really going on.

Kellie Pokrifka (34:43): With the appeals denial, one of our community members, Mark, asked: "Is it true that if you do have your appeal denied, you can never ever again apply for disability, even if it's 30 years from now or it's a completely different condition?" Is this true?

Stacy Monahan Tucker (35:05): Absolutely not. And that is the correct answer for both Social Security and disability through work. Social Security — you have four levels of appeals with Social Security that ultimately can end up in front of a district court judge. That can take two to three years. Most people are at least somewhat aware that Social Security will largely reject you in the first round. This is a situation where it actually, again, makes a lot of sense to get a Social Security attorney, which I am not.

Stacy Monahan Tucker (35:42): But Social Security has very specific rules about what a Social Security attorney can charge you. It's not that much money. They can, at most, take up to 25% of the back benefits owed to you with a limit of, I think it's now \$9,500. And \$9,500 is not nothing. But it takes that off of your plate and lets somebody else manage all of that for you, somebody who is familiar with the process and knows what needs to be done instead of trying to navigate it on your own.

Stacy Monahan Tucker (36:18): So oftentimes, by the time you get to the final administrative appeal, what's called an administrative law judge will agree that the claimant is disabled and approve. If an administrative law judge doesn't, then you still have one more opportunity. You can bring it in front of a district court judge and ask a district court judge to look. After that, you really are done. However, you're done for that claim.

Stacy Monahan Tucker (36:47): If you have another basis for disability at some point in the future, you can certainly make another claim based on that. Or if your current issues worsen and you're able to demonstrate that, you can make another claim starting from that new date of whenever you make it for the same issue. You just have to demonstrate that your medical situation has changed such that you believe Social Security will now understand from this new date forward you were disabled.

Stacy Monahan Tucker (37:20): And it's the same for your coverage. So long as you are still employed, if you make a claim for disability through your work and it's denied, you can make another one a year or two later. You can make another one three months later. It's just that you have to start from that new date. It won't keep considering it from the original date. That date's been ruled upon and is done. But you can have a new disability, including for the same symptoms, that has started and worsened at this new date. So yes, you absolutely can continue to make new claims.

Kellie Pokrifka (37:53): What did you mean with back benefits?

Stacy Monahan Tucker (37:56): Let's say you make a claim on January 1st and you say you became disabled on January 1st. Fill in all the paperwork and they deny your claim. It takes two or three months for them to get to a denial. They deny your claim. Then you appeal the denial and you have six months to appeal. I'm thinking about a private claim, but for Social Security, same thing.



Stacy Monahan Tucker (38:19): If you make a Social Security claim, and while they're looking at it, they still owe you from the date you claim to have been disabled. Social Security is a little more complicated because they have an internal rule: You have to be disabled for five months first before you can even make a claim; and they will only pay up to one year in back benefits. But they will still pay up to a year in back benefits.

Stacy Monahan Tucker (38:48): So back benefits — by the time they finally approve you, it could be two or three years. They will owe you for the amount of time that they were looking at all this, plus up to a year back before that. So that's considered back benefits. Back benefits are what they owe at the time benefits are finally awarded.

Kellie Pokrifka (39:12): So with SSDI, there is the “Blue Book” or the list of impairments. And a lot of people believe that migraine is not listed or isn't listed clearly enough. How does that make the process more complicated?

Stacy Monahan Tucker (39:25): It can be difficult for the same reason it's difficult to get it from a private insurance company, because it can't be easily verified. There's no test. An MRI does not confirm that you are having migraines. So anything that's pain-based that can't be independently verified, like a broken bone — insurance companies, and Social Security is a government insurance company, realistically — they don't like that.

Stacy Monahan Tucker (39:55): So that's where having lots of physician support comes in — being able to demonstrate that you've been treating regularly for this. And your doctors have tried all sorts of things. And your doctors can confirm that they've personally seen this. They have no doubt of the severity of your illness. I know there are hospitalization programs for severe migraine. If you can do that and your doctors are supportive, that is a good way to demonstrate that this is real. You've had to be hospitalized for this.

Stacy Monahan Tucker (40:31): So yes, you absolutely can. Migraines are something that is covered under Social Security. And also, migraines, as you surely know, come with a lot of comorbidities. And by that, I mean other health issues. Sometimes migraines are caused by these and sometimes migraines come as a package and nobody knows what's causing what.

Stacy Monahan Tucker (40:56): So you may have a TBI, which is causing your migraines. Those can be a lot easier to get a claim for because, again, with a TBI, usually there's some kind of physical evidence to demonstrate that this has happened. You've got a concussion; you've got post-concussion syndrome that's causing migraines. If you have documentation, it can be helpful. A lot of people with long COVID get migraines now. And long COVID, insurance companies love to push back on. If you can demonstrate that you have a confirmed COVID diagnosis, that helps.

Stacy Monahan Tucker (41:31): Being able to demonstrate an underlying confirmed cause that's contributing to the migraines can be very helpful when making a claim. One thing that insurance companies — and this is only private companies, it doesn't apply to Social Security — most private insurance companies have a two-year limitation on mental health benefits. Insurance companies like to try to shoehorn pain-related claims into mental health, so be aware of that.

Stacy Monahan Tucker (42:02): A lot of people have migraines and also suffer from depression or anxiety, which is very reasonable when you're living with a chronic pain condition. You're not disabled by the depression — or at least to the extent you are, the depression is caused by the migraine, which is a physical condition, not a mental health condition. So having to tease that out can come up a lot. That's not an issue for Social Security. Social Security doesn't have that limitation.

Stacy Monahan Tucker (42:33): So if you're disabled, whether it's a combination of mental and physical health, they don't care. They're just looking at all the bases for disability. The insurance



companies just have to provide what's in their contract, and more often they're including limits on mental illness. And recently they've been including limits on what's called self-reported limitations, which is a fancy way of saying pain, because pain can't be easily confirmed. And so they're also trying to put two-year limitations on pain-based claims, which includes migraines. It usually specifically says headaches in there as an example.

Kellie Pokrifka (43:13): This feels like an absolutely horrible and stigmatizing question to ask, but would not having our mental health diagnoses and comorbidities documented, would that help our claim?

Stacy Monahan Tucker (43:27): It depends. They will pay it for up to two years. So if it's your intention and you believe that you're going to improve, you're going to get better, but you need this break to be able to focus on your health, having the two years of benefits — regardless of whether it's approved because of your migraines or your mental health — could be what you need to get a handle on it all.

Stacy Monahan Tucker (43:54): I certainly would not want to encourage anybody to hide a legitimate disability that they're trying to manage because it could affect them in the long term. I also encourage at the end of that two-year mark where they terminate benefits, we often assist with appeals where the whole point of the appeal is they are independently disabled by this physical issue that is not related or caused by their mental health.

Stacy Monahan Tucker (44:24): And then we put together a whole appeal package explaining that, and that yes, they also have mental health issues, and we understand that that disability is limited to 24 months, but they are also independently disabled by this physical issue and they continue to need benefits for the physical issue. So that's usually how we handle it. And obviously, if you're so disabled that you are still needing it after two years, we want to help anyone keep that. But most people try really hard to get back to work. Most people want to be working. And so, yes, I encourage people to put everything out on the table and then deal with the issues as they arise.

Kellie Pokrifka (45:14): Going through the disability appealing process can be devastating. It can be overwhelming, isolating. It holds a stigma along with the stigma of migraine. Would you offer any advice for someone who's either considering whether to try to keep working or to try to appeal for disability? How can they deal with all of these overwhelming feelings?

Stacy Monahan Tucker (45:43): I would encourage people who are trying to make this decision to have an honest discussion with their doctor. A lot of times, people put their best face on when speaking with their doctor because nobody wants to admit that they're really struggling. And by the time they're in talking to their doctor, usually it's already pretty bad or you wouldn't be going to a doctor. And oftentimes, doctors, especially these days, are limited to a few minutes with you. And it's important to make clear to your doctor, "This is what I'm experiencing. I'm really struggling." That's where a headache diary or some other type of symptom tracker can be really useful to be able to quickly show your doctor in the limited amount of time you have: This is what I've been dealing with.

Stacy Monahan Tucker (46:29): And then you can talk to your doctor about whether — because for a lot of people, they keep pushing through when really if they took a short break to focus on their health, they would be able to reset and be able to figure out what their triggers are, what they need for their health and implement that, and then go back to work successfully. Where, if they're not giving themselves that space to do that, then eventually they can reach a point where maybe they get terminated because they're taking too much time, or they're too sick and they're not focused enough. And all of a sudden, they find themselves terminated. And you can make a disability claim then, by the way, but most people don't realize that. Most people aren't going to see this video.



Stacy Monahan Tucker (47:14): So all of a sudden, they find themselves out of a job because they were trying so hard to do their best. And they don't know what to do next. And they're convinced they can't work. And they don't know what to do. And it's just a spiral. And it also affects mental health. So talk to your doctor before it gets to that and see if it makes sense to take a break to figure out how to best manage what you're dealing with. And maybe you don't need to, or maybe you need to just go part-time for a short period of time. Or maybe you need to take six weeks and try an inpatient migraine program to see if that will adjust it. There's a lot of options out there if you're fortunate to have health insurance that covers it.

Stacy Monahan Tucker (48:03): So talk to your doctor and make that decision with them understanding what you're really going through and you thinking: What is this going to look like long-term for me? Is this a one-time short-term flare that's never happened before? Have I been living with this for years and it happens more and more, and I have to acknowledge that now? It's important to realize this is part of your benefit package. You wouldn't hesitate to use your health insurance. You shouldn't hesitate to use the other insurance that's literally there to take care of you.

Kellie Pokrifka (48:35): This has been so helpful. One, where can we follow your work?

Stacy Monahan Tucker (48:40): Let's see. My blog is at mtlawpc.com. And I do a lot of these interviews often with migraine institutions. So a quick Google of my name, Stacy Monahan Tucker, will likely come up with a lot of information. And one of the things that I've been trying to make sure people realize: As all of these layoffs are occurring nationwide, you can make a claim for disability even after being informed that you're being laid off. And that's true if you've been working part-time. And they are not allowed to terminate your benefits if you are already on disability and you get laid off. It's important for people to realize this, because with everything that's happening right now, you do have options.

Stacy Monahan Tucker (49:30): And if you're somebody who's been pushing through because you love your job and it's who you are, and then you get laid off, there's a really good chance you're included in the layoff because your symptoms are affecting your job performance, and you shouldn't be penalized for that. You have disability insurance for a reason.

Kellie Pokrifka (49:48): OK. And two, if someone is starting this process, even if they're just considering, "Should I do this? Should I try to fight through?" Are there any resources in particular you would suggest that they check out?

Stacy Monahan Tucker (50:00): The Social Security website, if you're looking at Social Security, actually has a lot of information on there about the process and how it works. You can also see what your benefit would be if you were to make a claim. For somebody who's thinking about it through work, I would encourage them to start with their human resources. Everybody wants to try to power through and look strong at work.

Stacy Monahan Tucker (50:26): They are required to give you accommodations if they're able to, and they are required to give you the information about the benefits available to you. So get that information. Educate yourself about what your options are so you don't find yourself suddenly scrambling after the fact. It can be a lot harder to gather this information once you've been terminated. So if that's on your radar at all, you want to gather your information while you're in control and you're making the decisions.

Kellie Pokrifka (50:57): This is perfect. Thank you so much, Stacy, for being here on the Migraine World Summit. It has been enormously helpful, and I really appreciate all the work you're doing for people like us who are really struggling.



Stacy Monahan Tucker (51:07): I'm happy to be here and happy to answer more questions if anyone has any. It's a big chunk of what we do.