



Navigating Employment Changes

Presented by:

Tom Stewart, MS, PA-C, JD

Melissa Barnhill:

Good evening, everyone. Welcome and thank you for joining MSAA's live webinar, "Navigating Employment Changes," presented by Tom Stewart. My name is Melissa Barnhill and I'm the Director of Mission Delivery and Community Engagement for MSAA and your host for tonight's program.

Just a little background about MSAA and some housekeeping items before we get started. As you may know, MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the entire MS community. Our services include a national helpline, providing English and Spanish services Monday through Friday, 8:30 a.m. to 8 p.m. Eastern time, as well as an equipment and cooling distribution program with products designed to improve safety, mobility, and to help with heat sensitivity. In addition, MSAA offers an MRI access program for individuals with MS who qualify for assistance. We also have educational programs, webinars and on demand videos, online tools, publications and digital resources. That includes the just released Ultimate Treatment Guide, which is now available on our website. This interactive guide describes and compares 19 FDA approved MS treatments and will help people living with MS make informed decisions and choices.

MSAA also offers support through community connection to help you stay connected with other members of the MS community. All of our programs are available to people living with MS nationwide. To learn more about MSAA's programs and services, please visit our website, mysaa.org or give us a call.

During tonight's program, you will have the opportunity to ask questions by typing them in the chat box. We will do our best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important, and it helps us in developing future programming and content. A link to the survey will also be included in the chat box. Please know that this program is for educational and informational purposes only and does not constitute formal recommendations. Please speak with your doctor or health care provider if you have any specific questions or concerns.

Now, without further ado, I would like to introduce you to our speaker this evening. We are extremely grateful to have Tom Stewart join us tonight. Mr. Stewart is a Social Security disability attorney, as well as a physician's assistant in Aurora, Colorado. As an attorney, he has a

decade of experience helping individuals with chronic disease receive Social Security Disability and other disability benefits. Mr. Stewart has also been treating patients with MS for 20 years and currently works within the Department of Neurology at the University of Colorado. Welcome, Tom.

Tom Stewart:

I appreciate that introduction. You know, I think I would just add to that over the years that I've seen how a little advanced planning might help to avoid some of the financial challenges that people face if they lose the ability to remain in the workforce and how advanced planning can help to avoid that. I mean, in some cases, a little planning and knowledge can help to avoid an otherwise financially ruinous situation. So this talk is intended to help people with MS who are still in the workforce plan for the possibility that their symptoms may someday cause them to lose the ability to work. And, of course, this information may also be helpful to people who are already in the process of trying to access disability benefits.

And I think it's important that I cover the risk of disability first, and by disability, I'm referring to an inability to work on a full time basis. I want to directly address the concern that I have when talking about this topic. I want to avoid the implication that all people with MS are necessarily going to lose the ability to work. Of course, I don't believe that at all. It's increasingly clear that many people with MS with good medical care will maintain normal or near normal function for their entire lives. But it's sobering to know that approximately one in four of all 20 year olds will lose their ability to work prior to retirement age. And there's another government resource, that's according to the Social Security Administration, there's another government agency that puts that number at one in three. And so to emphasize that, again, that's not restricted to people with a chronic disease, it refers to all 20 year olds.

So, and by the same token, though, I don't want to avoid the obvious and unfortunate fact that people with MS are at an increased risk of becoming disabled. One older study suggested that 45% of people with MS lost the ability to work after about 12 years. However, it's important to keep in mind that this data was collected prior to the widespread use of highly effective therapies that are currently available. So whatever the current risk for people with MS is, the point is that it is a good idea for everyone to know how to protect themselves should they lose the ability to work. And my hope is that nothing in this talk is discouraging.

Okay. And then another sort of preliminary matter is, before we get into discussing the main financial safety nets that people have, I want to mention what may be an obvious point. All of the systems designed to protect you in the case of disability sometimes fail. And so I think I'd be remiss if I didn't mention that family and friends remain the primary way that people are protected if they lose the ability to work. In my work, helping people who are trying to navigate disability, there is a very big difference between helping someone with a working spouse as compared to helping single people. The stakes are always much higher for single people, especially those that do not have private disability insurance, and they're applying for Social Security. And we'll talk more, of course, about each of those. But beyond that, the two main sources of financial protections, Social Security Disability Insurance and Private Disability Insurance. And I'll first talk about Social Security Disability Benefits before going on to talk about Private Disability benefits.

So the most important disability program for people with a work history by far is the Social Security Disability Insurance Program. And I'm going to be focusing on the weaknesses or challenges inherent in the SSDI program, because you need to know about them. But I don't want to be misunderstood. The protections afforded by the Social Security Disability Insurance

program are critical. And people with MS or other chronic progressive diseases and their families should be passionate about defending the program against its detractors.

Just think about what would be lost if you had to stop working. Of course, there are many factors to consider, such as loss of identity and social interactions. But the main, arguably the main damaging consequences of losing the ability to work would be loss of an income and often medical insurance. And SSDI can hugely mitigate the consequences of losing the ability to work by providing a modest replacement income ranging from \$1,000 for low earners to about \$3,000 for high earners as well as medical insurance in the form of Medicare. And additional amounts can be paid for children under the age of 18 living at home.

So almost all workers are eligible for SSDI benefits, assuming that they have worked long enough and recently enough. There are some exceptions, however. For example, some public employees and railroad workers pay into analogous systems and they don't have Social Security Disability Benefits, but they have other generally equal benefits. You're eligible for Social Security Disability Benefits if you've worked long enough, paid Social Security taxes, and importantly have worked recently enough. Most people who have a recent work history and have worked much of their adult lives don't have to worry about this. On the other hand, people who have not worked in the last five years or people who have not worked at least intermittently in the last five of the ten previous years, as sometimes happens among people with MS, they may not be eligible for SSDI. There are some, you know... technically someone needs to have worked in 20 of the previous 40 quarters to be eligible for disability insurance and there are special rules for people under the age of 31. But I think the main take home here, if there's any doubt about eligibility, about whether you have a consistent work history over the last five years, you should call Social Security to find out if you're currently disability insured. And also, you can create a MySSA account through Social Security's website and see the same information.

So if you can't prove that your disability began within five years of when you stopped working, you will not be eligible for benefits. Your application will be weak if you wait more than five years or even less, in some cases. This happens more than you would think and one of the key points to remember from today's presentation. I can easily recall a number of people who waited too long and were distraught about it afterwards when they realized they'd lost their opportunity to receive benefits. One woman didn't apply after she became disabled because she thought she and her husband had too much money, they'd be ineligible for financial reasons, and this is an error. Elon Musk, for example, would be eligible for SSDI benefits if he lost the ability to work. She regretted this, especially when her high earning husband lost his job.

Another woman didn't think she was disabled enough when she stopped working due to her symptoms because her symptoms were invisible, and this is also an error. The invisible symptoms being fatigue, cognitive problems, depression and pain. Although hers would be a more difficult case because her biggest problems were the invisible symptoms, which are harder to demonstrate as compared with, say, a gait abnormality, she made matters much worse by waiting until her disability became clearer. She waited more than five years. So if you lose your job due to MS symptoms, especially if you can't manage a 40 hour work week, you should not wait very long before applying, and certainly you shouldn't wait years.

SSDI's recent work requirement can also be a problem for people who leave the workforce voluntarily. This is a potential trap for stay at home or work at home spouses. I see this less often, but I want to emphasize that here I met a woman who stayed home with her young children and then planned to return to work years later when they were in elementary school, and when she became disabled, years after quitting her job to raise her kids, she was

devastated to learn that she was no longer eligible for disability benefits. In my opinion, this mistake is relatively easy to avoid. It's possible to maintain eligibility by working part time or intermittently. In 2022, earning just \$6,040 per year will maintain eligibility indefinitely. And this number is inflation adjusted and changes every year. Even earning less than \$6,040 per year by working very part time can extend the period of SSDI protection. And those who work for government agencies and public entities typically pay into a program such as Public Employees Retirement Association in Colorado instead of Social Security. In general, this is fine. PERA also pays disability benefits when someone becomes disabled and it's a fine substitute for Social Security. Occasionally, however, a significant problem arises when somebody who has paid into Social Security takes a break for a few years and then returns to work as a public employee, such as a teacher in a position where Social Security taxes are not paid. If someone makes this change and becomes disabled shortly thereafter, he or she may not be insured by either program and thus be unprotected.

Okay, so imagine yourself in this position - you've been white-knuckling it at work for the last year due to your MS symptoms and your boss has begun to notice that you're no longer keeping up with expectations. Let's make it more extreme and assume that you don't have a spouse and don't have private disability benefits. In my experience, this situation is not rare. You might want to apply for disability benefits and stop working only if you're found disabled, but unfortunately, it doesn't work like that. If someone is working for more than what the Social Security Administration considers to be substantial gainful activity, she is not disabled no matter how severe her symptoms. In 2022, substantial gainful activity is \$1,350 per month before taxes. And again, that number changes every year for most people. Most people make much more than that, and so for most people, the SGA rule means that they have to stop working prior to applying for disability benefits, which can be a terrifying thing to have to do.

So you might want to know how much money you would get per month. We already covered the range of monthly benefits, but it might help to know that the average is \$1,358 per month, so it's pretty modest. But the only way to find out the actual number would be to register on social security's website through the MySSA account or call Social Security to find that out. You might want to know how quickly you'll get that income, and it's important to know that your best case scenario is getting your first check after a five month exclusion. This is assuming everything goes like a perfectly executed shuttle launch and you get your benefits right away. Your best case for receiving a check is really six months because after the five months is when you get your first check. And that's assuming that Social Security makes its decision very quickly or relatively quickly.

You might want to know the odds of success and the appeal process at each level. So, of course, Social Security disability insurance is administered by the Social Security Administration, a federal agency. The federal agency contracts with a state agency known as Disability Determination Services, or DDS, which is the agency that makes the initial determination regarding disability. As you can see in this chart, the probability of success is not good. DDS only awards about 33% of all initial claims. So this is the best case scenario that I was talking about, maybe you can get a replacement check for your income in six months. That's assuming that you're among the 33% who get your claim awarded right away. This is based on information from 2017, and I assume it's not changed much and it typically takes 6 to 8 months to get a decision.

If your claim is denied, as is typical, the next step for you would be to request DDS reconsider your claim. So the state agency again. But you can see here that, for the reconsideration, your odds are even lower than the initial claim. And this can take another six months. Only about

10% are awarded at this level of appeal. If your claim is again denied by Disability Determination Services, the next step is to request a hearing before an administrative law judge. And that determination is made by a judge who works by the federal agency. So it goes back to the federal agency to make the decision about disability from the state agency.

In my opinion, you should get a lawyer from the beginning of this process to help with the initial claim. But that's arguable, but I think it's really not even arguable about whether you should get a lawyer when it comes to the hearing level. This is the first time you get a chance to explain how you're disabled in person. At the other levels, the decision is made based on paperwork alone. It can take an additional year beyond the other, the first six months and the second six months, so up to two years to get a hearing before an administrative law judge. And about 50% of claims are won at that level or some of the appeal levels beyond. And of course, the main takeaway here is it can take a long time to get an award. And in the end, some cases are denied entirely.

Okay. Let's turn to what I consider to be the most critical part of the lecture today, and that's how to prove disability. An MS diagnosis does not automatically qualify someone for disability without severe symptoms and limitations. A determination of disability, whether through Social Security or through a private insurance company, will largely depend on the extent to which your medical record conveys your severe symptoms and limitations. And only with a little bit of irony do I say that the truth doesn't matter, what matters is the medical record, which is a facsimile of the truth. Right? So a physician or other clinician's language stating that you are disabled does not help at all in Social Security cases. On the other hand, a physician's description of your specific limitations is very, very helpful, and this can be based on your medical history or on examination findings.

So, of course, your neurologist cannot include any information about your symptoms and limitations unless you specifically tell him or her. If your doctor doesn't write about your limitations, Social Security won't know about them other than by your self-report, which will probably be insufficient. You should know the difference between symptoms and limitations. Symptoms generally describe what you experience living with a disease. An example is fatigue, that's a symptom. If you have fatigue, you should of course mention this to your doctor and he or she would likely put it into your office visit notes. But that might not be enough and probably isn't enough.

You should also do your best to make sure that your limitations are documented, not just your symptoms. Your limitations are the "so what" of your symptoms. For example, a limitation might be needing to take a one hour rest or nap in the middle of the day due to the severity of your fatigue, or maybe the need to take breaks throughout the day, even after simple activities like taking a shower. Another limitation related to upper extremity and coordination might be difficulty typing or using a phone, it's not enough to say incoordination, but so what? So, I have difficulty using a keyboard or buttoning or zipping. And don't neglect symptoms and limitations that may be embarrassing, such as urinary incontinence or bowel incontinence a few times per week, as an example. And be sure to describe any difficulties with your activities of daily living, such as dressing, bathing, toileting or eating. And that's for a very severe case, and most cases aren't that severe. They've long ago stopped working. Or, often more relevant, are the instrumental activities of daily living - difficulty with shopping, housework, laundry, medication management or meal preparation.

So of course you need to visit your healthcare team primarily to get your medical conditions treated. But you should also keep in mind that you may need regular office visits, preferably with

an MS specialist also, to support your disability claim. If you do not seek care for a condition, then SSA may interpret that to mean that your condition does not limit you very much. So of course it's fundamentally a bad idea to not seek medical treatment, but it might affect you in unanticipated ways, including limiting your ability to prove disability, and I think that's especially true for people who have already received disability award, who then, you know, they kind of fall off following up with their doctor, and if Social Security decides to review the case and there's no medical record, they'll say... they'll end the disability and you'll stop receiving a check.

So there's a potential problem for people who rely heavily on telephone or email to communicate with their clinicians. Office visit notes, which are among the most important documents for supporting disability claims, are only created when you have an appointment with your provider. Sending emails or calling your provider may be practical at times, but such emails may not be available to support your claim. I have one client, for example, who had frequent seizures. And he would manage these by sending an email to his doctors who would then make medication adjustments as needed. And when he had his hearing, of course, all of the office visit notes were included in the record, but his emails, which contain most of the information about his seizure frequency, were not included, and the claim was much more difficult to win, only after an appeal to federal court and a second hearing.

Again following up with your neurologist and his or her recommendations is probably a good idea to stay well and avoid limitations and disability in the first place. But it's also important to think about your follow up from another perspective. SSA and Private disability providers may characterize your failure to follow up as noncompliance and use that to deny a disability claim. So, for example, if you're referred to physical therapy, you should try to follow up with this recommendation. But if you're unable to for, say, financial reasons, be sure to explain this to the referring source, usually the neurologist. And it's probably a good idea even to ask the neurologist to record the reason for your lack of follow up with the referral.

Be sure to follow up with all appropriate medical providers. For example, if you have cognitive problems, you should probably get evaluated by a neuropsychologist. If you have a gait disorder, you should be involved with physical therapists. And while primary care providers are truly invaluable resources, it's probably better to make sure you're involved with an MS specialist. If you have mood problems, you should follow up with a psychologist or psychiatrist, or urologic problems, follow up with a urologist. And then very importantly, if it's available and you're really close to seeking disability benefits, it might be useful to see if you can find an occupational therapist or a physical therapist who would perform a functional capacities evaluation and watch how your function changes over time. It's much more helpful than just a neurological examination, for example, which is just, you know, test your strength for a second. And most functional evaluations would measure you over time. And a lot of people with MS would experience a loss of function over time that might seem normal if tested just briefly.

Again, describing your primary limitations thoroughly and accurately at every visit is possibly the single most important thing you can do to increase the likelihood of a disability claim if one becomes necessary. In particular, you should also describe the challenges at work that relate to MS. For example, if you find yourself taking rests throughout the day or sneaking out to your car or something or working at home because you can take breaks as needed, you know, or keeping up with the pace expected of you by your employer, you should note these to your MS care team as soon as you can, even if these problems don't immediately threaten your ability to work. This kind of longitudinal history, history over time, is also important and more convincing to Social Security than limitations that appear suddenly in your record on the eve of a disability claim.

So how does Social Security determine disability? This is a complex topic, and usually a finding of disability will require you to prove that you cannot do your past work and that there's no other work you can do in the national economy on a full time basis. But I've included some more specific information here, but remember, these are just examples. The easiest cases are related to severe physical disability. For example, if someone needs bilateral support or a wheelchair for mobility, and this is clear from the record, he or she should be found disabled right from the beginning with an initial determination. Technically, this is known as a listing level impairment. Also, another listing related to MS is a combination of severe cognitive dysfunction and a milder but still severe gait limitation, such as needing a cane for balance. Again, that's another listing level combination. People who are 50 or over and are limited to sedentary work, being able to stand and walk only 2 hours per day, and unskilled work, capable of only simple, repetitive tasks, should be awarded benefits. However, age is very important in a Social Security claim, and for people under 50, this level of function would not be enough to justify an award of disability.

As a final example, and especially helpful for people who are under 50, would be being unable to work 8 hours per day, five days per week, reliably. This is usually the argument where invisible symptoms are the predominant problem in people who are under 50 years of age. And it's sometimes difficult to show that you can't work an eight hour day. This is partially because the neurological examination is so brief, as I mentioned before, it's just a few moments in time. And from Social Security's perspective, how can you have severe symptoms in the context of a near normal neurological examination? And the answer is, of course, you can, it's due to those, again, those invisible symptoms. So this gets back to what I was saying about describing limitations in your chart, such as the need to take breaks throughout the day. This is, you know, in your history is one of the ways you can show that you're not capable of working 8 hours a day, five days a week on a reliable and a continuous basis, and sometimes a functional capacity evaluation can be helpful in that regard as well.

So as I mentioned earlier, briefly, in addition to an income stream, people who get Social Security Disability Benefits will also get Medicare, but there's a 30 month waiting period from the date Social Security determines that your disability began. So clearly this is bad policy, the 30 month wait was thought by Congress to be acceptable because of COBRA rites, but often this is prohibitively expensive. During this period while they're waiting for Medicare, disabled people will have to find other solutions, such as getting insurance through a working spouse or the Affordable Care Act exchanges.

So, Supplemental Security Income is another similar program administered by the Social Security Administration, and this is for people who don't have a work history and are indigent. To qualify, briefly, to qualify, an applicant must have a limited income from all sources and have assets of less than \$2,000, for single people, excluding a modest home and a car. But the suggestions I have made regarding SSDI about how to improve your chances of success are the same for both SSI and SSDI as the rules for determining disability are the same.

Okay, now we're going to talk about Private Disability Benefits, which are obtained through private insurance companies. As a preliminary matter, note that the terms of private disability insurance, unlike Social Security Disability Insurance, are not codified in statutes and regulations. Private disability insurance is covered by contract and these contracts are variable. So I can tell you what is typical, but you would need to look at the specifics of your policy to be sure of any particular aspect of it.

So people who have been diagnosed with a potentially disabling disease like MS are generally unable to buy private disability insurance on their own in the marketplace, at least not at a reasonable price. Fortunately, many employers offer disability insurance as part of a compensation package without medical review. These policies adjust some of the shortcomings of Social Security Disability Insurance. Usually they pay more per month than Social Security, often 60% of someone's salary. So in the case of a high earner, much more. So, for someone who earns \$100,000 a year, \$60,000 would be the benefit and probably tax free. And compare that with, you know... it brings the number pretty close to what someone's full salary is. But compare that with Social Security, for a high earner, it might be \$36,000 a year total. And there are other advantages, too - the payments start almost immediately, as compared with starting in six months, as I mentioned. And there's usually a less restrictive definition of disability, which means it's easier to prove that you're disabled. So one of the main takeaways from this talk is not to decline these benefits if available. Sometimes an employer will provide an opportunity to increase coverage, for example, from 60% to 70% of someone's salary for employees who are willing to pay for it. Workers with MS or other chronic progressive diseases should strongly consider purchasing such additional coverage.

So, most policies provide an exclusion for pre-existing conditions. So if you get a new job and you have a diagnosis of MS, you would have a pre-existing condition when you start the job. But pre-existing conditions will generally not prevent claims for disability after the first year of work. Be careful, because time off from work, even under the FMLA, might not be included in this calculation. I had one 50-year-old petroleum engineer client who was going to quit work and apply for disability benefits at 11 months. I explained that her \$80,000 per year benefit, which was 60% of her salary, would be denied unless she waited another month and she spoke with her employer and the employer agreed to keep her on for another month. And so that small intervention was worth over \$1,000,000 to her over the course of her lifetime, or actually until her full retirement age, which is when most disability benefits stop paying.

And there are different kinds of private disability policies. The best policies provide benefits if you become unable to perform the essential functions of your current work, your own occupation, those are called "own occ" or "own occupation" policies. So, for example, a neurosurgeon with a tremor, only, may be unable to perform her occupation, even though there are other jobs she'd be able to do. Under an "own occupation" policy, she would be able to recover benefits because she can't work as a neurosurgeon. "Any occupation" policies require you to be unable to perform the essential functions of other work as well. So, if that neurosurgeon had an "any occupation" policy, she would not have been protected. Most plans are hybrid policies, they begin using a, "own occupation" definition but then convert to an "any occupation" definition after a period of time, usually two years. So that means that if your claim is initially awarded, the risky spot might be two years afterwards, when the definition of disability changes. At that point, if you are denied, you would certainly want to appeal and definitely get a lawyer to help with any denial of private disability benefits. Arguably, you could get one before you apply or as you're getting ready if you want some coaching. But most of the time, even given what I do, I'm not very cynical, most private disability policies pay in the first instance when they should. But, if there's a denial, certainly you should get professional help at that point.

So most long term disability policies require that you apply for Social Security Disability Benefits. It's possible that you may be found disabled for private disability benefits, but not for purposes of Social Security, because each of them uses a different standard for disability. In general, Social Security's definition of disability is the more restrictive one as compared with private disability benefits.

If you qualify for both long term disability and Social Security Disability Insurance Benefits, the monthly benefit you receive from Social Security will generally reduce the amount that you receive from the long term disability insurer. For most people who receive private disability benefits, an award of Social Security will not increase their monthly income. So you might think why bother? Well, it's still to do for a couple of reasons. One is that you would be eligible for Medicare if you're found disabled by Social Security. And then there's another reason that Social Security is important to private disability beneficiaries, and that is the "Disability Freeze," which is related to retirement benefits, but I think that's too fine a point to go into any further for this presentation. Suffice it to say that even if it's not going to result in more income to you at some point while you're getting long term disability benefits, you should apply for social Security at the very least to get Medicare.

Many long term disability companies encourage beneficiaries to apply for SSDI benefits using a particular representative, often not lawyers, and indicate that this is a free service. In my opinion, this is a bad idea, even misleading. You should get your own lawyer to apply for Social Security, even if you're already getting private disability benefits. In most cases, for reasons I won't go into, it will be free to you. In any case, the lawyer's fee comes out of what would have gone to the insurance company, in either case.

Some policies provide for partial disability benefits, which is very important to understand. If you lose the ability to work 40 hours per week, you may be able to work for 30 hours a week, keep your benefits and get paid, often 60% for the 10 hours per week that you're not working in that example. And again, that may be tax free. So, where available, this is an excellent way for people with a chronic disease to stay in the workforce despite the challenges of, especially, fatigue.

But without the benefit of partial disability insurance, be cautious about reducing your hours. By reducing your hours, let's say from 40 hours to 20, you may lose disability benefits because you're no longer entitled to a benefits package. And then if you become unable to continue to work part time, you may then, if you need to stop working, have lost the opportunity to collect disability insurance at all. So, and even if you keep your insurance benefit at 20 hours, as sometimes happens, you may reduce the amount you receive if you need to stop working entirely. So, I had a client who had good benefits, who worked for a hospital. She was struggling to keep up with a 40 hour work week, so she reduced her work to 20 hours per week for one month, and then she needed to stop working entirely. She was able to keep her benefits, including disability insurance, as I mentioned. And then her disability benefit, when it was calculated, was 60% of her reduced hours. So 60% of her new salary, which was briefly 50% lower than her full time salary. So in her case, it might have been in her interest not to reduce her hours, but simply to have applied for disability benefits.

Many people who are fired don't see that their symptoms are causing difficulties at work. It's sometimes easier to blame a jerk boss than it is to see that you have been making errors or that you're not keeping up with expected pace. It's best at least to consider the possibility that your symptoms are to blame, especially fatigue and cognitive dysfunction. Talk with your families and clinicians to get their input. If you're unsure, apply for benefits while you're trying to figure it out. Unlike Social Security, you don't have years to apply. You should apply right away, preferably while you're still employed.

I had a patient in the clinic who told me he was fired. So this is me as a physician's assistant, working as a physician assistant. And he was a patient. And so he was explaining how unfair it

was that he'd been fired. And I had some concerns about whether he had cognitive problems, even though he had never been formally tested. I asked him if he could count down from 100 by sevens, and he couldn't get to 93 without an error. It was very emotional for him and his wife, who happened to be in the office, also started to cry. I assume she already knew that he was struggling and she was crying because her husband had finally realized he had cognitive difficulties. Even though it was a few months after he was fired, I suggested that he apply for benefits, which he did, and ultimately he was awarded benefits.

So I looked at the questions that were submitted ahead of this talk, and a few of them were regarding accommodations in the workplace. And so I put together this slide, brief slide, because in general, what is and what is not a reasonable accommodation to your job is highly fact specific and difficult to address in this format. So I thought it would be good to mention this resource. This is the Job Accommodation Network. You can look up accommodations by disease, so you can look up, I mean, it's not just for people with MS, but you can look up MS, or Fibromyalgia, etc. and then you can drill down further and look at specific symptoms such as fatigue. And they might have, they'll have some ideas for job accommodations there that might help people stay in the workforce longer than they would have otherwise. And surprisingly, there's even excellent phone support, and for difficult questions as I've posed to them once or twice I was escalated up to people, experts who were able to answer my question. So it's a great resource to know about.

So I'd just like to thank the Rocky Mountain MS Center for the years of support they've provided. And also I'd like to mention that for those who are interested, I provide, I represent people for a fee which is highly regulated by the Social Security Administration, really, there's only one way to do it. And I'm privileged to be able to do that nationally. But I also offer free consultations for anyone who has questions, specific questions that can't get asked today. Feel free to call and we'll schedule an appointment at this number here: (720) 301-9708. And that's it. Thank you very much for your interest and attention.

Melissa Barnhill:

Thank you, Tom, for the informative presentation. Now to continue with our learning and our conversation, we'll go ahead and take some time for questions. We have a few questions that were shared during the registration process in tonight's program. Our first question is: "I have been on disability for ten years and have Medicare. If I do return to work now or in the future, would I be able to go back on disability at the rate I receive now? If I have to stop working again, I am single and do not have or had disability insurance."

Tom Stewart:

Okay, so there are a few issues in there. So, the one interesting piece that comes to mind is that you would continue to get Medicare for years, I think it's five years, after you go back to work. And then there is an expedited process for reinstating disability, if you need to go back on disability benefits. Of course, that's designed to encourage people to do just what you're thinking.

And then would it be the same amount of money? Yeah, approximately. The amount of money is calculated by some inflation adjusted earnings over your lifetime up to 35 years, I think. So if you make a different amount of money, presumably less, it might affect your benefit if you go back on disability, but probably not very much.

Melissa Barnhill:

Okay. Our next question is: "I'm starting a new government position that offers long term disability benefits, which I have signed up for. I suffer from fatigue but I'm embarrassed to admit it. What can I do to protect myself if the symptoms and limitations get worse? I started two weeks ago."

Tom Stewart:

Okay. So yeah. Okay. I mentioned a few things tonight. One is the, you know, for thinking about accommodations, the Job Accommodation Network, JAN. The Ask JAN website, and there's a phone number on there I would call to see, to generate some ideas for how you can stay in the workforce. The disability policy, again, I can't say what every disability policy is, you can't look it up as you can on Social Security's rules, but most disability policies would exclude MS for one year, not counting FMLA time. So if you can make it past a year, with them counting aggressively against you, you might have disability insurance that might be partial, as I mentioned, and then if so, then you might be able to reduce your hours and even be paid 60% tax free for the amount of time you're not working. So that's very fact specific, and you'd have to do some more research to clarify any of that. Hopefully, that helps answer some of what you asked.

Melissa Barnhill:

Thank you. You sort of touched on this, but someone else asked: "What evidence is required to prove disability when there are invisible symptoms?"

Tom Stewart:

Right. This is right at the heart of what I do. Right? Is how do you do that? One way as to make sure that in your history, when you're seeing your clinicians, especially your neurology team, you're describing your symptoms there and your invisible symptoms and not just the symptoms, as I mentioned, the limitations. So what? You have fatigue. That's a hard one, right? So because the neurologist can't measure that, but they can record what you say. And that's a lot better than you saying it to a judge when it's not in your medical record. So in the history is one answer. That's how you prove fatigue. And then another way is, you know, it's, again, it's hard to find good people to do this, but sometimes to get an occupational therapist or a physical therapist to do a functional capacity evaluation and observe the way fatigue impacts your function over time, that's pretty convincing sometimes, especially when a neurologist agrees with it. And then for cognitive problems, it's very important to seek neuropsychological testing. That's really the answer to that. And pain, getting treated. Right? I don't know, depression, another invisible symptom, you know, getting treated by appropriate specialists is the best you can do. I hope that helps.

Melissa Barnhill:

Let's see here. "What if I want to look for a job, try working for a while, and then suddenly I have a relapse and have trouble walking and seeing? How can I get reinstated and start getting what I was getting before I started to work?"

Tom Stewart:

That's pretty similar to the other question. There are incentives to get back, you know, to get people who are disabled to go back into the workforce, and some of them include getting disability again in the future more easily. And you continue to get Medicare for a few years. Sorry, I don't know that exact number off the top of my head.

And regarding the money, as I said before, yes, if you go back for a long time and you're earning less, it might somewhat reduce the benefit over time, it would be inflation adjusted at the end of the day, anyway. But accounting for that, yeah, there might be some diminution of what your benefit is, but it would take years and probably the amount that you would earn in excess of the Social Security payment you're currently receiving by working would far outweigh any small reduction in the amount you receive from Social Security if you become disabled again. I hope that helps, too.

Melissa Barnhill:

Thank you. "Can I receive disability when I'm working full time?"

Tom Stewart:

No, no. If you're earning more than the number I showed on the screen, it's about \$2,200, sorry, I don't know the number. \$2,000, let's say, per month is... Gosh, how can I've forgotten this? I use it every day. Let me just Google... Oh, I can't do that. Anyway, the amount that you would earn working full time, even at minimum wage, is in excess of what social security would consider substantial gainful activity, and you would not be eligible to apply for it no matter how severe your symptoms. So, you'd have to reduce your hours under SGA, and just Google "SGA 2022" to see what that number is.

Melissa Barnhill:

Okay. "I have MS. It's not very noticeable and no need for any accommodations. Is it safe to disclose it in a new job when asked, or is that too risky?"

Tom Stewart:

I don't see any upside in it. I think you might encounter some prejudices, people who might make assumptions that you do have some problems when, as you know, you don't. So I don't, I mean, it's just, you know, I actually have one patient who told me she did it, she disclosed... she was working as a dental hygienist teacher. And she had some limitations, she had balance problems, and she wanted people to know why she had balance problems, that she wasn't drunk. And so she did disclose, and that worked out fine for her. So very fact specific. But my view is don't invite the potential prejudice by disclosing when there's no need to.

Melissa Barnhill:

Right. Well, I think that's all the time we have for questions this evening. Thank you so much for this informative presentation and for providing us with insightful information about navigating employment changes. And to our wonderful audience, thank you so much for participating.

This concludes our webcast. Tonight's webinar was recorded and will be made available on our MSAA MSi-website in the upcoming weeks. Please take a couple of minutes to fill out the survey that will soon appear on your screen and know that we are always thinking about the MS community and we hope that you and your family continue to stay safe. Thank you and have a wonderful night. Bye now.