

# Balancing Government Assistance and Career Goals



When forced to rely on government assistance to access lifesaving therapies, you can fulfill your ambitions without fear of losing benefits — if you speak up and get the right people to hear your concerns.

**By Whitney L. Ward**

**EMBARRASSMENT AND** shame. That's what I felt when someone asked what I did for a living. I rambled on about focusing on my writing career or taking time to volunteer, hoping it would appease curiosity. It was a somewhat truthful answer, but it didn't tell the whole story — a story I tried to hide. I couldn't work because I receive government assistance to get my treatments and medication to live, function and experience a good quality of life. And this assistance dictates the amount of income I can receive, which is very little.

No matter the reason, there *is* a stigma against people who financially rely on the government. I can't tell you how many times I've been in mid-conversation with a person when they said something like, "It makes me so angry that my tax dollars are going to people who don't work, sit on the couch all day

and play on their phone." At those times, my feelings are a mix between wanting to disappear and wanting to educate these people on the factors I had to consider when making the difficult decision to seek government benefits. But the latter would give away my secret, and I feared I would be stigmatized.

No employer could ever provide adequate insurance to cover a fraction of my medical costs. I didn't have the luxury of choice; I elected to receive government assistance because it was my only option. I was forced into a system of bureaucratic red tape with ridiculous and unrealistic salary caps — one that penalized me when I tried to work and threatened me with lower or terminated benefits if I made more than approximately \$530 a month. As a result, I struggled to make ends meet. Even working as a substitute

aid threatened my Medicaid and Social Security Insurance (SSI) benefits. It bewildered me that the same government benefits that make it possible for me to receive treatment that gives me the health and strength to work also prohibited me from working due to fear I could lose those benefits. The incongruity was unfathomable.

I reached out to government officials, but I was held at arm's length. They were also overwhelmed with the red tape that had accumulated over the years. Often, I would be shuffled to other government agencies that gave different answers and no consistent solutions. It became exhausting, and I didn't know how to proceed since no one seemed to know the right path to gain independence and still get the help I needed. I couldn't risk it, and I believed I would be stuck forever with no purpose or ability to advance a career.

Then, about a year and a half ago, I was filled with righteous indignation, and I decided I would not be demoralized any longer by the need for financial assistance that treated an illness I didn't ask for. I had a college degree in creative writing, I felt called to be a writer, and I was passionate about making the most of my story. I would no longer accept the sad message the government had given over the years, which was I was only good enough to merely exist because I was created to do so much *more* than just exist. I finally understood staying silent would produce no change, and tenaciously and diligently making my voice heard was important to facilitate discussions and solutions. The more I raised awareness, the more I discovered I wasn't alone. My doctors confirmed they had many patients who were fighting a similar debilitating system. Fellow patients in the chronic disease community confided to me how disheartening it was to choose government income and insurance to access their treatments for survival rather than pursue their dreams and passions. It saddened me, and it made my mission bigger than me — it was for the greater good.

After years of research, fighting and learning the frustrating government healthcare system, I want to share with others in the chronic illness community the golden nuggets I have gleaned. Finding a path is difficult and exhausting, but it isn't impossible. It is my sincere wish this advice will make others' journey less overwhelming and fill you with hope that change is possible because you were created to do *more!*

## 1) Falling Through the Bureaucratic Cracks

Unfortunately, at times, people fall through the bureaucratic cracks of government assistance. According to [medicaid.gov](https://www.medicaid.gov), as of August 2020, more than 69 million

individuals were enrolled in Medicaid. The Centers for Medicare and Medicaid Services reported 15 percent of individuals with disabilities were enrolled in Medicaid in 2019, and those expenses were the largest. That's a lot of people with unique conditions and reasons for needing government assistance to supervise.

Many recipients who receive Medicaid, which Job and Family Services monitors, qualify for government insurance because the Social Security Administration granted them SSI. Therefore, these recipients are receiving federal and state aid, which can be very confusing and complicated because it becomes necessary to keep track of two separate salary caps, rules and regulations while deciphering how the two types of benefits overlap.

If that isn't enough, in my experience, caseworkers are overwhelmed with the guidelines and, therefore, are not qualified to advise their constituents on the parameters. I can't tell you how many instances over the years I've spoken to a caseworker to inquire what my salary cap was or if there was an incentive program in which I could enroll so I could enter and advance in the workforce, and each caseworker gave me a different answer. To add insult to injury, the federal and state agencies did not work well together, contradicting and questioning each other's information and competency. It was maddening, and it squelched my determination to get answers, thus forcing me to come to terms with feeling there was no way out of the system. Many immune-compromised patients receiving government benefits tell me they have experienced the same confusion.

So, how do you combat and rise above the discrepancies you can't control but could penalize and jeopardize your medical coverage if you try to better yourself? Be your own advocate. Just as you research your illness, expect the proper care and treatment from medical providers, and voice your concerns, you need to advocate for your healthcare. And to do this adequately in a broken system, you need to keep meticulous records. Document and file every piece of paperwork you receive from the Social Security Administration and Job and Family Services, especially the paperwork showing the agencies' errors. Furthermore, when you speak with different caseworkers, write down their names and the answers they give you.

It's especially crucial to record if a caseworker inappropriately insinuates you should 1) never get married, or you'll lose your healthcare, or 2) if you are married, you need to divorce and live separately from your significant

other so you can keep your benefits. Sadly, this happens quite often. Amanda Childress, a West Virginia native and mother to 13-year-old Jadalyn who has severe chronic illnesses that require her to take many expensive treatments to survive, reports: “Darin and I were told to divorce and live in separate households to get help. Jadalyn meets the disabled guidelines for SSI, but Darin makes too much money for any benefits.” How much more money? A minuscule \$13. More proof of a flawed system.

If a caseworker makes similar statements, be sure to ask for his or her name, and note the date. Every time you turn in verifications or have a meeting, file the slip you are given with your number because it lists the date and time you were at that particular office.

Another layer of good recordkeeping I have initiated during the COVID-19 pandemic is the importance of a follow-up email after a phone conversation. This is vital because the email has the details of your phone conversation and the information you discussed with your caseworker that can't be disputed.

Keeping in-depth records can be overwhelming and exhausting, but the fruit of your labor is worth it because your efforts will tell a story and show your truth when you are given a chance to voice your concerns to the right people.

## 2) Getting the Right People to Hear Your Concerns

Now that you've kept the records needed to prove what you've experienced, the next step is getting to the right elected officials who will listen to what you have to say and begin the conversations that will foster solutions and change. Truthfully, it isn't easy to get a meeting with state and federal representatives on your own. I tried multiple times. I was either held at arm's length, given perfunctory answers or passed on to another agency. For example, the state Job and Family Services led to even more of a dead end for me because it and my local office contradicted each other's information.

I'm not trying to discourage you. I merely want you to have a realistic understanding of how the system works so you can take the correct steps at the beginning and aren't tempted to quit. The key is finding an advocate who can help build a bridge to the right government officials who create policies and laws, and that person is at the local government level. In the county in which I live, there are commissioners, who may be referred to as something different depending on where you live. Commissioners are policymakers for the county,

and they are the supervisors of Job and Family Services. These commissioners usually have good relationships with state and federal senators and representatives, and they have a desire to help their county and constituents.

I connected with one of my commissioners, shared my experiences, and in two months, I had meetings with the aides of a congressional senator and representative, as well as an in-person meeting with Congressman Brad Wenstrup, who has a unique perspective on government assistance since he is a physician. “One of the reasons I ran for office in the first place was because I saw people making healthcare decisions who never saw a patient or dealt with these government programs,” he explained. “It's important that we, as representatives in government, hear directly from those directly impacted.”

I went from no access to more access than I have ever been granted because of the advocate I found in my commissioner. Now, my commissioner and Congressman Wenstrup are working on issues and solutions to make the system better, to lift the unrealistic and outrageous salary caps, and to educate the local caseworkers about programs and policies so constituents receive the correct information. We are even in the process of incorporating state senators and representatives in these conversations. Of course, federal officials focus on federal benefits, and state officials focus on state benefits.

I advise you to contact your commissioner's office to set up an appointment. Go into that meeting knowing what solutions you're seeking and what questions you want to ask. Take your records and use them as a visual while you share your story. End your meeting by asking your commissioner to facilitate meetings with policymakers at all levels of government. Having a locally elected official's belief and support in your cause will go a long way to assist you in speaking to lawmakers who have an effective chance of making things better for those of us in this broken system.

## 3) Don't Stop Fighting

Once you've kept extensive records, made the necessary connections with an elected official, and have begun seeing progress, what's next? The most important step: Don't quit fighting or tenaciously pursuing *more*. If I had quit in the midst of confusion and conflicting information, I would have never connected with the right people who could give me the right answers.

What has become invaluable is the open communication I now have with Congressman Wenstrup's top aide. She has continued to keep me updated on the progress the congressman's office has made with fellow policymakers, and since I am someone who has personally experienced the broken system, she is constantly asking for my input on effective solutions. She also connected me with a counselor through the State Vocational Rehabilitation Services Program agency who explained the programs I qualify for and gave me *The Red Book*, which describes in-depth what the programs offer. Sadly, this book is not well-known, which adds to the misinformation recipients receive.

The professional relationships I have formed have enabled me to illuminate the discrepancies I have received from representatives at the local agencies who supervise benefit recipients. I now have people in my corner who make sure caseworkers who penalize me due to incorrect information are held accountable. I have discovered the "ins and outs" of the federal 1619(b) plan (continued Medicaid coverage for those receiving SSI benefits prior to returning to work) and

a state program called Medicaid Buy-In for Workers with Disabilities and how they can be improved. Because I didn't quit fighting, I now have the attention and respect of people who can implement needed changes. "Medicaid and Social Security can be complicated to navigate, and it's important we keep hearing from those we represent," said Congressman Wenstrup. "Some key policies we've enacted are because constituents reached out to us with issues or ideas."

Just think of the changes patients could benefit from if you decide not to quit. This country could have more people entering the workforce to not only help strengthen the economy, but also to empower people to know their self-worth, and give them the gift of hope. There is a path to *more*, and we were created to embark on it. 

**WHITNEY L. WARD** was not only the first person in the world diagnosed with MAGIS syndrome, she had the honor of naming the new primary immune deficiency. MAGIS means "more" in Latin, and Whitney hopes to instill in her readers the message they are more than their disease. Find out more about Whitney's journey at [www.whitneylaneward.com](http://www.whitneylaneward.com).

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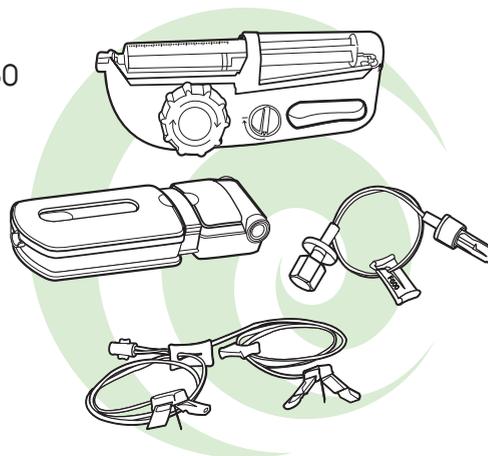
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