

A Light at the End of the Tunnel Brenda's Story

It was the summer of 1996 when things fell apart. Brenda's memory about what happened is patchy, but she recalls a menacing sense of dread. She began hearing voices that competed for space in her brain. She saw and believed things that weren't real. When her boyfriend brought her to the emergency room, she was admitted into a psychiatric unit for the first time. Brenda remembers being consumed by a feeling that the whole world was conspiring against her.

"It was really one of the most horrific things I had ever experienced," she recalls. "I was emaciated, sleep-deprived and paranoid. I thought people in the hospital were trying to kill me and hatched a plan to escape."

For the next 3 weeks, the 19-year-old continued to experience psychosis — a frightening symptom of certain mental illnesses that causes people to hallucinate and hold on to strange beliefs, blurring the lines between delusion and reality.

"You experience all the terror, confusion, bizarre images and thoughts that you have in a nightmare," she explains. "Only with a nightmare you wake up, while with psychosis you can't just open your eyes and make it all go away. It's awful."

Rollercoaster

Brenda was diagnosed with schizoaffective disorder, a chronic mental illness that commonly includes symptoms of psychosis, anxiety and depression.



There had been signs when she was younger, such as mood swings and difficulty organizing her thoughts, but these milder symptoms went overlooked and didn't stop Brenda from working in retail throughout high school.

Faced with the more severe symptoms of schizoaffective disorder, Brenda realized that she needed to focus on her health and recovery. After her diagnosis and release from the hospital, Brenda applied for Social Security Disability Insurance (SSDI) and embarked on a decades-long search for effective treatment. Symptoms recurred during the 18 years that followed her first episode, interfering with her ability to maintain work and live on her own. Brenda was in and out of the hospital between 1996 and 2014 and saw a succession of doctors who prescribed medications that addressed some symptoms while causing sedation, swelling and lethargy. She tried to balance unpleasant sideeffects with keeping her symptoms under control. It was extremely challenging.



Still, Brenda managed to earn a small amount of money working part-time jobs where she discovered her own caregiving competencies and "people skills." She helped people with Alzheimer's disease and then found work at a mental health service provider. She used her personal experiences to lend support to others and discovered the therapeutic benefits of focusing on someone else's needs. It felt right, and Brenda decided to go to college to study human services — a set of undergraduate studies in social sciences that primes students for careers supporting underserved populations (such as social work, vocational rehabilitation, and counseling).

After graduating from the University of Maine in 2006 with a Bachelor of Science, Brenda's personal growth and self-discovery continued. She found that improved treatments, teamed with strategies like avoiding triggers, mantras and focusing on work, helped experience longer stretches of health.

"I learned to stay away from the news and R-rated movies," she recalls. "I also figured out how to live with some hallucinations, distinguishing those that are not real. They don't go away, but I ignore them."

"My anxiety tended to come once a day and would last for 15 minutes. When the wave inevitably hit, I'd grasp onto the Serenity Prayer. If I could just hang on and ride it out, then I knew I'd be done for the day," she says. "I'm not saying these experiences aren't difficult, and I'm not trying to imply it's a simple 'mind over matter' thing. But each day I got through gave me confidence, and my coping skills grew stronger."

Brenda noticed a connection between work and her recovery, and by 2014, she felt ready for the pride and the paycheck that go with consistent employment. But she also knew that with a chronic condition, the road to recovery is littered with setbacks. She had relied on SSDI and Medicare benefits for so long that full-time employment felt like a major risk. Brenda knew she needed help, and that was when information about **Social Security's Ticket to Work (Ticket) program** arrived in the mail.

Social Security Work Incentives

Work Incentives act as a safety net to help you as you transition to work.



Expedited Reinstatement (EXR)

is for people who successfully return to work and no longer receive Social Security disability benefits. If your cash payments ended because of earnings from work, and you stop work because of your disability within 5 years of when your benefits ended, you may be able to have your benefits started again through a request for EXR. Through EXR, you can receive interim benefits for up to 6 months, while Social Security reviews your claim. These interim benefits do not have to be repaid if the claim is denied.



Continuation of Medicare Coverage for SSDI Beneficiaries

Most people with disabilities who work will continue to receive at least 93 consecutive months of Hospital Insurance (Part A); Supplemental Medical Insurance (Part B), if enrolled; and Prescription Drug coverage (Part D), if enrolled, after the 9-month TWP. You do not pay a premium for Part A. Although cash payments may stop due to work, you have the assurance of continued health insurance for 7 years and 9 months. To qualify, you must have a disability, already have Medicare, and be working at the **SGA level**.



Medicare for Persons with Disabilities Who Work (SSDI only)

If your Medicare stopped due to work, you continue to have a disabling impairment, and you are under age 65, you can buy continued Medicare coverage. If you have limited resources, you may be eligible for state assistance under various Medicare Savings Programs. Your state Health and Human Services agency makes the determination about whether you qualify for this help.

You can learn more about Work Incentives in Social Security's Red Book at www.ssa.gov/redbook.

Find a qualified Benefits Counselor who can help you understand how Work Incentives apply to you. Call the Ticket to Work Help Line shown at the end of this feature, or use the **Find Help Tool**.



Ticket to Work and Work Incentives

The Ticket program supports career development for people with disabilities who are ready for employment. Adults age 18 through 64 who receive Social Security disability benefits qualify. Through the Ticket program, State Vocational Rehabilitation (VR) agencies and service providers known as **Employment Networks** (EN) offer a range of free services to help people prepare for, find or maintain employment. Some ENs serve people with a specific type of disability. Others offer certain types of services. The Ticket program is voluntary and set up to help people gain financial independence.

Brenda called the Ticket to Work Help Line and asked whether earning more money would mean losing her SSDI; how she could find help getting a job; and what would happen if her disability interfered with work again. The representative was able to answer many of Brenda's questions and sent her a list of service providers to help her find career supports and services. Brenda then connected with the Maine Career Center, an EN that could help her navigate the transition to full-time employment.

The first thing Brenda needed was help understanding the risks of full-time employment. A professional at the Maine Career Center told her about Social Security Work Incentives. Work Incentives make it easier for adults with disabilities to explore work while continuing to receive Medicare or Medicaid coverage and in some cases, cash payments from Social Security. Because Brenda received SSDI, she would be able to test her ability to work during a 9-month Trial Work Period (TWP), while receiving benefits. After her TWP ended, a 36-month Extended Period of Eligibility (EPE) began. During the EPE, most people with a disabling impairment get benefits for months in which they earn less than \$1,220 — Social Security's definition of Substantial Gainful Activity (SGA) in 2019. Brenda felt at ease knowing she would have time to determine how full-time employment would work for her.

"My EN educated me about possibilities I didn't know existed," she says. "They were... instrumental in helping me find full-time work which, I realized, helped me maintain better mental health. When you are vulnerable, a little encouragement goes a long way. I was a mousy, scared little thing when I went into [the Maine Career Center] and they were effective cheerleaders. I'm grateful to them for helping me see that I'm stronger than I thought... and for pushing me in a direction that ended up being such a success."

More than 20 Work Incentives make it easier for people to enter the workforce. Because each person's circumstances are different, job seekers are encouraged to consult a **Benefits Counselor**, a qualified professional a qualified professional who can help people who receive SSDI or Supplemental Security Income (SSI), due to a disability, make informed decisions about employment.

Service Boot Camp



Brenda's EN worked with her to develop an **Individual Work Plan** (IWP), a road map designed to help her reach her employment goals. She received career counseling, help with interview skills, assistance with

resume writing and job leads. In 2015, she landed a job as a call center representative for Time-Warner Cable. "I developed [strong] customer service skills," she recalls. "...and I was promoted to a full-time position as Quality Assurance Supervisor!"

As she worked with customers, managed complaints and fielded questions, Brenda found she was good at conflict resolution. "I had good rapport with coworkers and customers alike," she says. "My anxiety abated as my confidence grew...and it felt great to be contributing."



Thriving

Brenda believes that employment has been a critical ingredient in helping her achieve consistent improvement in her mental health in recent years. She also credits the help she received through the Ticket program with setting her on a good path.

Brenda's experience as a Quality Assurance Supervisor prepared her for the next position she secured, with help from her EN. As a Community Rehabilitation Counselor, Brenda brings together her passion and her service skills to help vulnerable populations transition from a group home into a place of their own. She helps people cultivate community connections and independent living skills, proudly noting that she has turned her personal history into an asset.

"Ticket to Work gives you a chance to put yourself out there, even when you're unsure," she continues. "When you have the kind of support that allows you to focus on succeeding, you discover what you can do! I don't know what the future will bring. But with the [Ticket] program and personal growth, I have more confidence than before that I have the tools to keep moving forward. Symptoms will come back and when they do, I will hang on... knowing there will be a light at the end of the tunnel."

"The recovery I'm experiencing while helping other people acquire empowerment and independence has been amazing," she reflects. "Peer support is one of the most successful therapeutic environments for people with mental illness. To be effective... to really understand what is required to overcome the unique obstacles people with mental illness face, you need to have been there [yourself]. This work is not just about making money. The interactions with people create sharing and friendship... it's a healthy environment and I'm thriving in it."

Ticket to Work and Work Incentives helped Brenda find her path to a better future.

Find yours! To learn more, call the Ticket to Work Help Line at 1-866-968-7842 or 1-866-833-2967 (TTY), or visit choosework.ssa.gov.

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