

Circadian Rhythm & Blues: Shirley's Story

Shirley remembers the first time it happened. On a Saturday in 2008, while driving her 10-year-old son to the mall, she was overcome by sleepiness and a slackening of her muscles. For seconds, her body seemed to go on automatic pilot as she lost awareness of what she was doing.

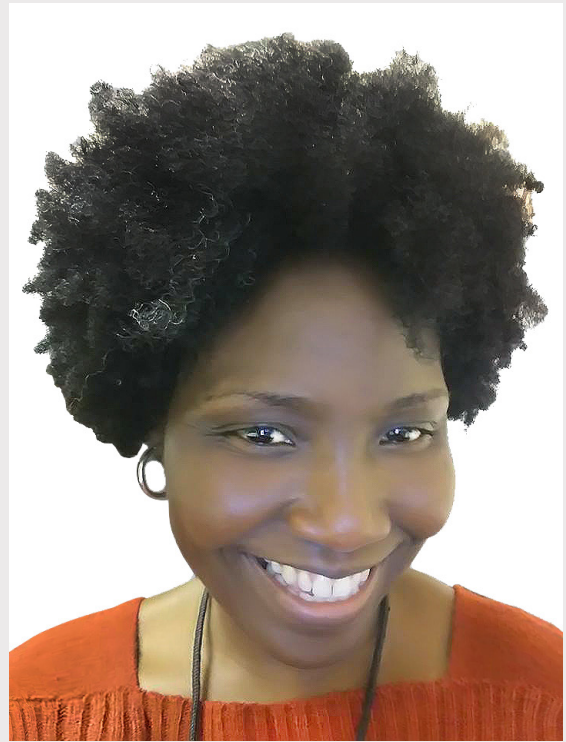
"I was on the Pennsylvania Turnpike," she recalls. "...and I had fallen asleep at the wheel without realizing it. My car veered into the adjacent lane."

When a loud, urgent car horn snapped her back into consciousness, Shirley corrected her steering just in time to avoid a collision at 65 miles per hour. The episode lasted seconds and then Shirley felt fine. It was a strange incident that she put out of her mind, until other odd episodes started happening.

"I began to fall asleep in the middle of conversations," she explains. "... and then I had a second incident when I fell asleep while driving. Co-workers found me sleeping at my desk. Throughout that year, it felt as if my world was caving in."

Bad Dream

Shirley sought help from a neurologist who specializes in sleep disorders. A person's circadian rhythm includes physical, mental and behavioral changes that follow a daily cycle. This includes a natural sleep cycle of sleeping at night and being awake during the day. After a sleep study, the neurologist diagnosed Shirley with narcolepsy, a chronic disorder related to circadian rhythms that affects the brain's ability to control sleep-wake cycles.



In hindsight, she remembers earlier signs of excessive daytime sleepiness. However, she says, "...I just figured as a working mother of young children it was normal to be tired all the time."

Faced with more frequent and severe symptoms that interfered with work and led to the loss of her driver's license, Shirley needed to focus on getting her condition under control. She had to leave her job as a Medicare investigator and apply for Social Security Disability Insurance (SSDI). It would take 6 years to find effective treatment.

"It was the first time I lost my independence," she recalls. "I was accustomed to caring for others and it was distressing to lose that sense of control over my life. It was very stressful making ends meet on an SSDI check. I began to feel hopeless."

A diagnosis of **clinical depression** was added to narcolepsy. Shirley saw a succession of specialists who prescribed different medications to address her complex symptoms. It was a long, hard road.

“The medications I was on were toxic to my body,” she reflects. “I was suffering more from their side effects than from the symptoms they were meant to treat. It was discouraging and frustrating.”

After years of treatment that added headaches, nausea, weight gain, and hallucinations to her symptoms, Shirley decided to try something drastically different. She consulted a team of doctors that included a nutritionist and a holistic medicine professional. They recommended an alternative approach to improving Shirley’s wellness.

“I went through a detox. Under my doctors’ supervision, I stopped taking most of the medications that were causing problems,” she recalls. “I switched to a vegan diet, **exercised** 5 days per week, and participated in a consistent program of **meditation**.”

Shirley learned to manage her chronic condition by adapting multiple aspects of her life. She’s in bed by 9 p.m. to ensure she is getting enough rest. She takes nutritional supplements and vitamins to help with alertness. “I lost weight and gained peace of mind,” she says. She now falls asleep less frequently during the day and has fewer depressive episodes.

“Narcolepsy is not something that just goes away,” she explains. “It’s a struggle every day. But I’ve learned to make adjustments in my life to work around the disability.”



Ticket to Work Service Providers

Several different types of Ticket program providers can help you transition to the workforce or progress in the job you have:



500+ **Employment Networks (EN)** across the U.S. offer a range of free support services through the Ticket program. Some ENs serve specific populations, while others provide specialized support services. ENs can help you:

- Prepare for the workforce
- Find a job and stay employed
- Advance in your current job
- Get job accommodations
- Stay in touch with Social Security
- Stay organized



Benefits Counselors are professionals who can explain how working will affect your Social Security disability benefits. Community-based organizations, known as **Work Incentives Planning and Assistance (WIPA) Projects**, have benefits counselors on staff. Some ENs also offer benefits counseling services.



Workforce ENs are providers that are also part of a state’s public workforce system. Workforce ENs can give you access to a wide array of employment support services, including training programs and special programs for youth in transition and veterans.



People who need more significant support services, such as rehabilitation or training, may find help at a **State Vocational Rehabilitation (VR) agency**. Their services are designed to provide the client with the training and other services that are needed to return to work, to enter a new line of work, or to enter the workforce for the first time. State VR agencies can help you get ready to work. If necessary, you can then find an EN to help you keep your job and make more money.

Use the **Find Help** tool to connect with providers that offer the services you need to start or advance your career.

Revival

Having found routines and treatments to improve her health, Shirley felt ready to try work again. She looked forward to getting out of the house, earning an income, and contributing to her family's well-being. But her desire to return to the workforce came with concerns about whether anyone would hire her. Like so many people who have been out of work for years, Shirley had lost her self-confidence.

"One day, I received a letter in the mail from an employment agency called **America Works**," she recalls. "They invited me to attend a job fair where I would meet people who could help me better understand my options and make a transition back to work. I thought it couldn't hurt to check it out, so I went."

When she met representatives from America Works, Shirley learned some news she could use.

They told her about Social Security's **Ticket to Work** (Ticket) program. The Ticket program supports career development for people with disabilities who are ready for employment. Adults ages 18 through 64 who receive Social Security disability benefits (SSI/SSDI) qualify. Through the Ticket program, service providers known as **Employment Networks**, (EN) offer a range of free services to help people prepare for, find or maintain employment. America Works is 1 of hundreds of ENs across the USA authorized to assist Ticket to Work participants. The program is voluntary and set up to help people gain financial independence.

Shirley felt connected with the America Works team and chose them as her EN. The first thing she needed was help understanding the risks of employment. A Benefits Counselor at America Works educated her about Social Security rules and programs called **Work Incentives**. Work Incentives make it easier for adults with disabilities to explore work or gain experience while continuing to receive Medicare or Medicaid coverage and, in some cases, cash payments from Social Security. Because Shirley received SSDI benefits, she would be able to test her ability to work during a 9-month **Trial Work Period** (TWP), while

Safety Net Work Incentives



Expedited Reinstatement (EXR) is for people who successfully return to work and no longer receive Social Security disability benefits. If your cash payments have ended due to earnings from work and you need to stop working due to your disability within 5 years of your benefits ending, the EXR can help you receive benefits without filing a new application. EXR allows you receive 6 months of temporary cash benefits while Social Security conducts a medical review to decide to reinstate your benefits. You may also be eligible for Medicare and/or Medicaid during this temporary benefit period. Typically, the temporary benefits do not have to be repaid if the claim is denied, but you can learn more in Social Security's Red Book.



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 benefits 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



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. Shirley’s benefits would not end as soon as she went back to work. She would have time to determine how full-time employment would work for her.

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 who can help them make informed decisions about employment.

Government Work



Shirley’s EN worked with her to develop an **Individual Work Plan (IWP)**, a road map designed to articulate her employment goals and help her reach them. She had a background in government program administration and decided to pursue job leads from local government agencies. To help her adjust, America Works first helped Shirley find a temporary administrative job with the city of Baltimore. Shirley says it felt great to get out of the house again, be productive and interact with coworkers. It wasn’t long before she landed a permanent position in **procurement and logistics for the state of Maryland**. The professional procurement staff for Maryland General Services perform contract administration on behalf of all consumers of state government goods and services.

Throughout 2015, Shirley’s self-confidence was restored. Her EN helped her advocate for **reasonable accommodations** that helped her adapt and succeed at work. Shirley’s anxiety about whether she would have the skills and stamina to work full-time were gone by the end of the year.

“I’m grateful for the help I received through Ticket to Work, particularly the support from professionals at America Works,” she says. “It’s comforting to know they are there to answer my questions, and to remind me, ‘you’ve got this,’ at times when I need encouragement.”

In 2017, Shirley landed a new job as the Compliance Officer for Maryland General Services, where she wears many hats and has more responsibility. “I help ensure that small, minority-owned, woman-owned and veteran-owned businesses are represented on state contracts. This work has given me a sense of purpose,” she says.

Employment has restored many of the things Shirley felt she’d lost years ago. Work has, in part, helped her maintain consistent improvement in her mental health and well-being.

“It feels wonderful to have my independence back!” she continues. “I’m getting a certification in government audits so I can continue to grow in my career. I feel like I can rely on myself again. I’ve escaped the black outlook that weighed me down years ago. There are now bright colors on the canvas of my future!”

Ticket to Work and Work Incentives helped Shirley 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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Social Security’s Ticket to Work program