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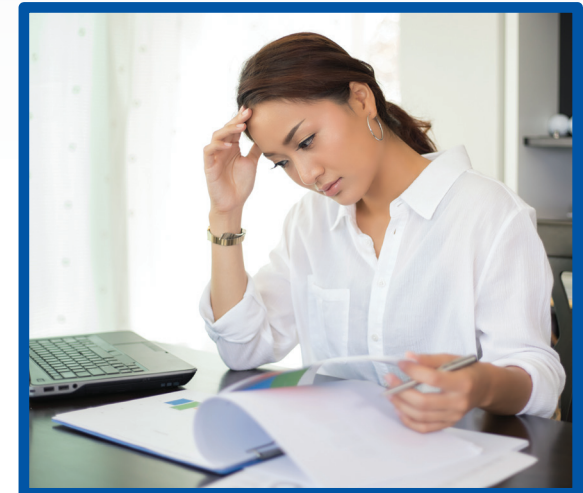
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Employment and MS

The Challenges and Opportunities



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Employment and MS

The Challenges and Opportunities

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Funds for publishing Employment and MS: The Challenges and Opportunities have been generously provided through an educational grant from Genentech.

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About MS

Multiple sclerosis (MS) is an unpredictable disorder that can cause a variety of symptoms, which for many, can flare up and then subside over the course of days, months, or even years. While MS is not contagious, its causes are not yet fully understood and researchers continue to search for answers.

MS is most frequently diagnosed in young adults, although individuals of any age may be diagnosed with this neurological condition. Particularly with today's approved treatments and wellness strategies, most individuals with MS are able to live a full and productive life, with much hope for the future.



Introduction

Living with multiple sclerosis (MS) and staying in the workforce can present many challenges. Thinking about one's needs, in advance, is important when trying to cope with these challenges. To help avoid a crisis, individuals may consider how much their symptoms are currently impacting their daily life and how personally meaningful their work is for them.

Clearly, most people work to sustain themselves, and not all are able to ask if their work is meaningful or brings joy and a sense of purpose to their lives, beyond paying the bills. However, in this day and age, you will find many different ways to work by exploring alternatives and accessing resources that can extend your participation in the workforce – regardless of your personal motivations. Doing so will help you adjust to your “new normal.”

The purpose of this booklet is to help people assess their current work situation and to conceptualize where they are, where they might want to make changes, and how to access available resources if choosing to alter their employment path. In addition to providing information on the work environment, this booklet also focuses on one's personal work identity, the impact of symptoms, improving communication with one's neurologist, life outside of work, the Americans with Disabilities Act, reasonable accommodations, and Social Security benefits while working. Insightful questions and helpful resources are also included at the end of this booklet.

In the Workplace: Cultural Expectations and Norms

A variety of workplace environments exist. Organizations and industries usually have existing expectations about what is “normal” in a particular environment and measures for meeting these expectations. Even with those companies that have manuals and written guidelines dictating the climate of the workplace, the culture of these companies may still have unwritten and unspoken assumptions that are not discovered until one becomes more familiar with the organization.

Those work expectations that are overt (or obvious) might include details such as arriving on time, having no overtime pay, locking the building no later than a certain time (such as 5:30 pm), having no one on the floor alone, and similar mandates. Rigid work environments can make requests for accommodations more complicated, discouraging requests to deviate from these norms. Some work settings are even more rigid, and despite existing labor laws, workers are implicitly discouraged from taking breaks or leaving work for lunch. Conversely, some work environments are more relaxed and allow employees more freedom with their schedules and daily routines.

The sections to follow address the different workplace environments. Details are also provided on making a proactive change, if appropriate.

EXPECTATIONS BASED ON “ABLE-BODIED” CAPABILITIES

“Normal” is a cultural aspiration. This becomes challenging if MS symptoms alter “normal” functioning. Normalcy is valued and encourages following rules, not standing out, and not deviating from the status quo.

However, in spite of policy changes, workplace settings are often “ableist.” Ableism is the notion that most people are able-bodied, so public and private spaces are set up without considering the variety of needs that people living with various levels of function and abilities may have. Being able-bodied is considered the norm. Hence, the responsibility is on the individual who is deviating from the norm, to request changes within work environments.

The adjustments requested by the employee force the burden onto that individual, necessitating that he or she be identified as someone who is not a part of the system – an outlier. This is regardless of the fact that a significant number of people are impacted by disability at some point in their lives.

**According to statistics reported in 2010
by the United States Census Bureau:**

19 percent
of the population is disabled, with more than half reporting “severe” disability

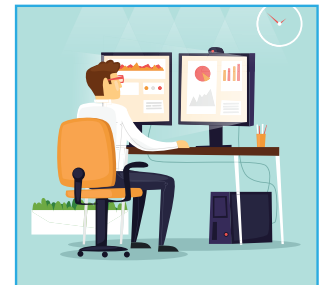
41 percent
of these disabled people, ages 21 to 64, were employed

Roughly
30.6 million
people have difficulty using stairs and use an assistive device, such as a cane, crutches, walker, or wheelchair

ASSESSING THE CLIMATE OF SPECIFIC WORKPLACE NORMS

Telecommuting, video and phone conferences, as well as flexible hours, can all help to decrease commuting time and increase productivity. Flexible schedules can enable people to work around fatigue and other symptoms, allowing for breaks or different start and end times. Using vacation time, sick time, personal time off, and family leave can also help to keep a healthy balance and prevent over-exhaustion, burnout, or an MS pseudoexacerbation (a temporary worsening of MS symptoms, often caused by an unrelated illness, stress, or a rise in temperature).

Employees with physical limitations need to consider the accessibility of the office buildings. For instance, different entrances may exist that are more accessible, and a different office space that is better suited and currently underutilized could possibly be made available.



Workspace comfort is another issue that needs assessment. Factors to consider include: the appropriateness of the seating, computer, and desk area; the size and privacy of the office or cubicle; how much noise comes into that office; and whether or not the office has windows – if so, would over-heating or direct sunlight be an issue?

An employee may want to request an “ergonomic/work-station assessment” of his or her workspace as a first step. This is when the employer has a workspace reviewed for comfort and safety to protect workers’ health and to avoid worker injuries on the job. OSHA, the Occupational Safety and Health Administration, regulates safety in the workplace and can be a helpful resource if you have questions about your safety at work that are not being answered by your employer.





The location of restrooms is another consideration. In some instances, these may be located outside of office suites, requiring a longer walk. Making a request and moving closer to a restroom can decrease distress – particularly if mobility and issues with bladder or bowel function are concerns. The same is true for being close to an exit, especially in case of an emergency.

In some settings, the Human Resources Department is an asset and a helpful place to make inquiries about resources and accessibility. Employees may observe the experiences of other co-workers to assess whether or not a consultation with Human Resources is a risk or a safe option when making plans for the future in a certain position.

Workplaces vary in terms of how Human Resources is managed. Your observations, employee manuals, and the assessment of the rigidity or flexibility of your own workplace will give you a sense of how risky it is to reveal you are living with a disability. Employees in some work environments feel comfortable seeking resources within their workplace, while others feel their livelihood could be threatened with any personal disclosure of information about their health status.

Depending on the structure of your position and the climate of your workplace, asking for help may be discouraged or misinterpreted. Sometimes starting the conversation with your neurologist, mental health provider, occupational therapist, or physical therapist can be helpful in clarifying your needs and your degree of confidence.

MAKING A PROACTIVE CHANGE WHEN NEEDED

Some people enjoy their career and/or derive some type of personal satisfaction from the work they do, while others do not. If you belong to this latter group of individuals who neither enjoy nor derive satisfaction from your job, you may benefit from pursuing a new career that inspires you. Making changes driven by passion rather than fear can be empowering.

If appropriate, this could be a time to re-evaluate your current job and be proactive about what direction you take in the future. With honest reflection, people can identify changes in their capacity to perform certain assigned tasks. Some changes in function may indicate the necessity for changing a position within one's current work environment or possibly moving out of a particular industry.

Leaving a job voluntarily can be frightening. However, with support, resources, and planning, it can also be exciting. The following are two examples of some real-life proactive changes made by two individuals with MS:

- A scientist with young children was expending so much energy at work that he found he was deteriorating physically. After taking an early retirement, he downsized his home, relocated to be closer to other family members who could provide support, and practiced better wellness strategies, such as eating a healthy diet and participating in physical therapy. As a result, he became more involved in his children's daily activities, lost weight, and improved his walking ability.
- A "Type-A" (less-relaxed) saleswoman was unable to keep up with the daily demands of her job. Unfortunately, she was not fully aware of how her body was being impacted by MS and disregarded the onset of new MS symptoms. Because she (and her doctor) had no record of her symptoms, she was ineligible for disability insurance once she was no longer able to perform well at her job. As a result, she was forced to reinvent herself and found a new career in real estate – where she could create her own hours and address her personal health needs.

Personal Work Identity

Culturally supported beliefs, aimed at able-bodied individuals, focus on individualism and not needing help. Examples of some familiar culturally supported beliefs include: work hard and don't quit; work your entire life; don't let other people down; don't depend on others; don't ask for help; and if you have a problem, solve it yourself. Of course, while we often strive to be self-sufficient and work hard, such rigid beliefs are difficult to sustain, and can lead to feelings of guilt or a sense of failure if we do not meet such high expectations. Learning to take breaks and identify ways to reduce unnecessary stress may include knowing when to ask for help.

Living with MS can challenge one's personal identity and clash with workplace norms.

- Attachment to roles can be mistaken as a definition of self; if someone is no longer able to move through the world the same way, with the same title, he or she can lose a sense of connection and purpose.
- Type A personalities (less-relaxed individuals who are always busy and feeling a sense of urgency) struggle to let go of constantly working, being on the move, and getting things done. If the rhythm changes, it can lead to a great sense of loss.
- Individuals need to consider their comfort level with disclosing their disability to people at work and understanding why it would or would not be helpful to disclose their needs to others. For instance, having an ally at work when feeling stressed can be helpful, while telling someone who gossips can make someone feel threatened or vulnerable.
- Individualism is paramount, yet in so many ways, humans are interdependent. They may not acknowledge or realize how much they may actually need others in order to perform many of their activities. As we move through our days, systems of people are in place, providing resources to keep us going. For example, farmers harvest food for our meals, mechanics keep our cars running, vendors sell products we need (and want!), schools educate and care for our children, and transportation departments keep the roads accessible and functioning. Without these hidden and expected services, our independence would look quite different.

MS Symptoms and Their Potential Impact at Work

While MS has the potential to cause several different symptoms, the specific symptoms each person experiences vary greatly. Medications are available to treat many MS symptoms, and these may include over-the-counter drugs as well as prescribed medications. Diet and exercise may also be helpful with managing certain symptoms. All treatments or changes in diet or exercise should only be done under the guidance of a qualified physician.

MS symptoms are often compounded by extreme fatigue, which may be worse in the afternoon, sometimes relating to a rise in body temperature. Some symptoms may be temporarily increased by heat intolerance – a classic MS tendency, where a rise in temperature (internally or externally) causes a person to feel much worse. Keeping cool through air-conditioning or various cooling devices, such as those offered by MSAA's Cooling Equipment Distribution Program, may be helpful for people with heat-sensitive MS.

When recovering from a symptom flare-up or learning to cope with a change in mobility, rehabilitation through physical therapy and occupational therapy can be of great value. Speech therapy, therapeutic exercise, and certain medical devices may also be useful in dealing with the symptoms of MS. Some of those who have a physically demanding or highly stressful job may choose to make a career change, in which case vocational training is helpful.

When a family member receives an MS diagnosis, it can disrupt the roles and dynamics in a family system. Participating in some type of counseling program can help family members adjust to the new realities of living with MS. People react differently to the diagnosis and seeking professional assistance helps to identify the concerns and needs of those involved.

Unfortunately, anxiety and depression can be a part of MS. While feeling shame about emotional issues or needing help is not unusual, people may be comforted to know that almost everyone experiences such issues at one time or another; that these emotions are often beyond our control; and that no one needs to feel ashamed. During challenging times, increasing support and developing new coping strategies are essential. Counseling services are confidential and can provide the help you may need. If you have other concerns, you can always address them with your neurologist, another trusted physician, or even ask questions of a mental health provider.

Individuals with MS may experience one or more of the following common symptoms:

- **Physical symptoms include:** balance problems; bladder dysfunction; bowel problems; muscle spasticity (stiffness); sexual dysfunction; speech difficulties; swallowing disorders; tremor; as well as walking and mobility issues.
- **Emotional, mental, and psychological symptoms include*:** anxiety; cognitive changes; depression; and pseudobulbar affect (PBA – a neurologic effect characterized by sudden, uncontrollable expressions of laughter or crying without an apparent trigger).
- **“Invisible” symptoms include:** dizziness/vertigo; fatigue; numbness; pain; sleep issues; Uhthoff’s syndrome (the temporary appearance of symptoms resulting from heat stress); visual disorders; and weakness.

A neurologist helps individuals to identify and manage their symptoms. However, people may not know what types of accommodations are best suited to them in light of the symptoms they are contending with in their daily life. This is when consulting with an occupational therapist may be helpful to discuss the types of accommodations that may be requested in the workplace.

To follow are examples of possible workplace accommodations:

- If fatigue sets in later in the day, a request to adjust one’s work schedule to begin the workday earlier may be helpful in maintaining productivity.
- Physical changes in balance, dizziness, or weakness could indicate a need to request closer parking and/or easier access to the building.
- Bladder or bowel incontinence may indicate a need to be in a work area that is located closer to a restroom; this may also identify the need for more frequent restroom breaks.
- Changes in cognition (i.e. focus) can be impacted by noise and other distractions; requesting a workspace away from a high volume of activity and noise can increase the ability to focus.

** Please note that depression and anxiety can occur more often with MS. For some, severe depression, substance abuse, and social isolation from living alone are additional risks. Anyone experiencing these types of symptoms, or care partners who might suspect this of their loved one with MS, should immediately contact their physician or therapist. These types of symptoms are treatable. When untreated, such symptoms can potentially increase the risk of suicide. If such thoughts are suspected, please contact the National Suicide Prevention Lifeline. Trained counselors are available 24 hours per day, seven days per week, at the following toll-free number: (800) 273-TALK (8255). Information may also be found on their website at www.suicidepreventionlifeline.org*



Reporting to the Neurologist

We are accustomed to replying to the question, “How are you?” with “I’m fine.” What appears to be an inquiry has actually become a polite greeting; keep it simple, don’t complain.

This sometimes transfers to the doctor/patient interactions. Whether one shows up to an appointment feeling better than usual, or better than last week, or not wanting to share the challenges of complying with treatment plans, it can be tempting to present as a model patient. To be praised for doing what is asked of you can feel good, but this can lead to not getting one’s needs met or underreporting symptoms.

Reflecting on how you feel when visiting the doctor can be helpful. For instance: Are you afraid? Feeling rushed? Intimidated? Unsure of medical terminology? Developing insight, creating a strategy for appointments, and planning for neurology appointments can help decrease stress and provide a full and more realistic picture of symptoms.

In the two sections to follow, helpful tips and strategies are given to assist with preparing for and visiting with your neurologist. These sections explain the importance of accurately recording and reporting symptoms, while providing details on how to ease stress and improve communication.

ACCURATELY RECORDING AND REPORTING SYMPTOMS

Fear of disability and change can sometimes interfere with one's awareness of symptoms. This is a form of denial, and denial can at times be a coping mechanism. However, avoiding or not recognizing symptoms can lead to poor reporting to the neurologist, and this means that the symptoms will not be recorded accurately at appointments, not to mention possible deterioration of health due to untreated symptoms.

Reporting symptoms accurately increases opportunities for healthy interventions and can also help identify if other health issues might be involved, such as regular aging or menopause. Lifestyle changes and referrals to appropriate resources – which include consulting other professionals for physical, speech, occupational, or mental health therapy – can often help to alleviate a number of symptoms and decrease any distress or discomfort.

Paying attention can be tiring, so simplifying how symptoms are tracked can be very helpful... and there's an app for that! Using mobile apps can assist in the regular tracking of symptoms, along with keeping a list of questions, so each appointment with a neurologist can be maximized. This can include photos or videos, recorded on your phone, of symptoms that may be observed visually.

One example of an app designed specifically for people with MS is My MS Manager™, MSAA's mobile phone application, which is provided free of charge to individuals with MS or their care partner to use on their iPhone or Android mobile phone device. Developed in conjunction with @Point of Care, this first-of-its-kind app for MS offers individuals a convenient and effective tool to manage the ever-changing course of the disease.

This special app allows users to track disease activity, store medical information, and generate charts and reports across various metrics such as treatments, moods, and symptoms. Other HIPAA-compliant features include optional private reminder settings, links to further educational materials from MSAA, and the ability to connect to physicians and other clinicians via the app to share progress and reports securely and as needed. For more information, please visit mymsaa.org/mobile.



EASING STRESS, IMPROVING COMMUNICATION, AND FINDING SUPPORT

Medical appointments can be stressful and bringing along a relative or friend to appointments can be comforting. Some MS symptoms such as anxiety and forgetfulness, or the possibility of being too focused on one issue, can reduce one's ability to remember the answers to questions and instructions given by the neurologist. Including a trusted family member or friend to take notes allows the person with MS to focus on asking questions and listening to answers.

Prior to appointments, you may want to reflect on how you are functioning in all areas of life – including work, family, and hobbies. This can help you to focus on your level of functioning and how some abilities may have changed. By identifying the changes you are experiencing, your doctor will be better able to provide proper treatment for your symptoms. Additionally, this will lead to better recordkeeping, and accurate medical records can be helpful in painting a picture of medical history when asking for accommodations or possibly applying for disability insurance in the future.

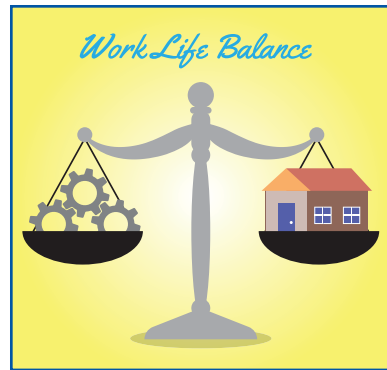
Just as workplaces have expectations and norms, doctors and medical centers also have their own systems and procedures in place. Establishing the best means of communication with physicians and the interdisciplinary healthcare team between appointments decreases crisis escalation and supports wellness. Examples of ways to communicate include email, website portal, and speaking to the nurse. Learning when and whom to contact if symptoms become problematic can be helpful. As with any relationship, communication can be challenging, so knowing how to best communicate and having a system set up in advance when life is calm can be important.

Understanding the policies for requesting medical records can also preempt urgency and avoid a crisis. Clinics and physicians have varying policies and costs related to copying medical records, so by being proactive and not procrastinating, undue urgency can be avoided.

Educational programs, support groups, online communities, and other resources for bringing people together and understanding the symptoms and changes related to MS are available to members of the MS community. Decreasing isolation and increasing knowledge can promote a healthy lifestyle and develop important coping skills. A wealth of information is also available through websites, educational videos and webinars, publications, and more. Along with other organizations, MSAA provides many vital resources to the MS community. For more information, please visit mymsaa.org or call MSAA's Helpline at (800) 532-7667.

Life Outside of Work

Balancing both work and life together is vital to wellness. Below are some basic self-care considerations:



- Getting adequate sleep and rest
- Taking time to exercise and play
- Scheduling time to shop, prepare food, and cook
- Staying active socially with family and friends
- Devoting time to religious and/or spiritual commitments
- Incorporating pleasurable activities, such as volunteering, visiting with animals, and spending time outdoors

These self-care suggestions are not new concepts, yet they are complicated for most people to implement into daily life. While many talk about wellness, the demands of work and family life often disregard the need for prioritizing the care for oneself and can be perceived as “selfish.” Somewhere between selfish and selfless is self-preservation. Perhaps this is a continuum of care that is personal and can be adjusted for each individual. Conceptualizing a personal plan for wellness and self-care is something that can be facilitated with a mental health professional or an occupational therapist.

Self-assessment is an important part of determining what changes are needed for the future. To follow are examples of areas to consider:

- Assess if the current job is new or long-term, and whether your capacity and function are up to par.
- Assess changes in function, such as changes in cognition, gait, and levels of fatigue; also ask those close to you to assess any changes they have observed.
- Examine how work and home activities are progressing; what you plan and what might actually be happening may be two different things, and in some cases, this reality can be painful, frustrating, or conversely, a relief.
- Consider if your own identity is related to your roles at work, and if these roles are difficult for you to change; this can sometimes lead to poor decision-making.
- Be aware of your inner dialogue and self-talk; self-compassion and being kind to oneself can decrease the discomfort that can accompany change.

Review your history of coping with discomfort and the unexpected. If unhealthy coping habits were supportive in the past – such as using alcohol, drugs, smoking, overeating, or social isolation – consider alternative support options for the future. Simplify the activities and issues you can control in your life to reserve energy for more important things.

Finances are another important part of determining what changes are needed for the future. Rent or a mortgage as well as the expenses of daily life, must all be figured into the equation. Paying off debt, and possibly college loans, may also be a part of your financial goals. Another significant responsibility is if you are supporting other family members, such as young children, young adults (possibly with college expenses), and elderly parents; when other people are depending on you, this can greatly limit your options for changes in employment.

When considering finances, you will want to look at your earning potential in the coming years, and if applicable, the age when you may anticipate going on disability. You’ll also want to look at your long-term goals, the time when you plan to retire, and other ways that you may be able to earn money. If possible, downsizing or cutting back, as well as changing one’s lifestyle, may be necessary for your future financial security.

Financial wellness is also personal. Have your dreams been put on hold? At different times in life, aspirations and goals might need to be reassessed. Knowing that stress and chronic illness are not a good match, re-evaluating the needs and wants of financial obligations can shed some light on what is essential moving forward.

Not all people in the workforce are able to leave when it is determined that a current job is no longer a good match. However, resources are available that can help guide workers to other available industries and sometimes assist with training for new skills. Please see the resource section at the end of this booklet for more information about possible career counseling, changes, and training.

Ultimately, you will want to determine what matters most in your own personal circumstances. Consider your age and stage of life along with your expectations for personal accomplishments. Reassess your lifestyle in terms of quality of life and determine if you spend enough time with people who add joy and enhance your quality of life.

Americans with Disabilities Act and Reasonable Accommodations

The Americans with Disabilities Act (ADA) was established in 1990 and was written to protect both employees and employers in businesses with 15 or more employees. The intent was to create an inclusive workplace providing a framework to make the workplace accessible for people living with disabilities.

The way the legislation is written requires decisions to be made on a case-by-case basis. Presumably this allows for equal opportunities in selecting and hiring qualified applicants with disabilities and inclusive access to promotions and benefits.

“REASONABLE” VERSUS “UNDUE HARDSHIP”

The request for making an accommodation is the responsibility of the employee who needs the accommodation. This requires the employee to identify his or her needs and what accommodation(s) will be needed to resolve these specific needs. While you may know to some degree what your newly presenting deficits are, you may not know what the solutions are to assist you.

Please note that the employer is not the one responsible for identifying the solution to accommodate a certain need. What is required to request an accommodation for a disability is as follows:

- 1) You will need to state that you have a disability and make an official request. **However, this does not mean that you need to disclose your actual diagnosis, but you must identify the need due to a disability.***
- 2) Explain how your disability interferes with your ability to do your job functions, that is, the job for which you were hired.
- 3) You must also identify the accommodations you need in order to continue performing your job functions. The request must be “reasonable,” meaning that it will not cause “undue hardship” to the employer to meet the request.

**Requesting a letter from your neurologist identifying your disabilities can be done without disclosing that you have an MS diagnosis.*

WORKING PROACTIVELY TOWARD REQUESTING REASONABLE ACCOMMODATIONS

Deciding to ask for accommodations can feel daunting, but it is a process that needs to be approached one step at a time. All of the preceding sections in this booklet were designed to help you to think in advance of what you want to do and the best way to achieve your goals. By doing so in advance, when the time comes to ask something of your employer, you have already done some of the important preliminary reflection.

Knowing if you are still able to perform the job you were hired to do – with a few adjustments – is a good place to start. If the job has left you dissatisfied for any reason, knowing the benefits of staying... or leaving... will be very helpful when making choices. Reflecting on your work history in the company is important, as well as identifying and articulating the value you add by staying on with the company. This can lead to a positive discussion about your value to the organization.

Whether or not you can identify what your needs are or what accommodation might be essential, getting a referral for an occupational therapist (OT) could be valuable. Occupational therapists are professionally trained to help people make adjustments to maintain a good quality of life. You do not have to do this alone.



Social Security Benefits While Working

The Social Security Administration has programs in place to help individuals with disability to get back into the workforce. These include work incentives as well as its “Ticket to Work” programs. Additionally, if receiving Social Security disability benefits or Supplemental Security Income (SSI), certain rules allow people to continue to receive their monthly payments while working.

Social Security’s work incentives include:

- While working, individuals may receive continued cash benefits for a certain amount of time
- While working, Medicare or Medicaid may also continue (certain rules may apply)
- When starting a new line of work, individuals may receive help with education, training, and rehabilitation

Social Security’s “Ticket to Work” programs include:

- Vocational rehabilitation
- Training
- Job referrals
- Additional employment support

Overview of Social Security’s work incentive programs:

- **Trial work period** – this allows individuals to work for at least nine months to evaluate their ability to work while continuing to receive Social Security benefits; however, to avoid too much income and having to make a repayment, please consult the Social Security Administration in advance for specifics
- **Extended period of eligibility** – gives individuals an additional 36 months (three years) in which to work and continue to receive Social Security benefits, provided the earnings are not “substantial”
- **Expedited reinstatement** – when an individual’s benefits have stopped because he or she has been earning “substantial” income, this person has up to five years to restart the benefits if unable to continue working
- **Continuation of Medicare** – when Social Security benefits have been stopped because a person is earning “substantial” income, if still disabled, the individual will continue to receive his or her free Medicare Part A coverage for at least 93 months (almost eight years)

- **The deduction of certain work expenses related to one’s disability** – for individuals with a disability who work, they may be able to deduct certain expenses from their monthly earnings, such as seeing a counselor, needing a taxi, or purchasing assistive equipment

Please note that individuals who receive Social Security need to contact the Social Security office if anything changes with their employment status. These include: starting or stopping work; experiencing a change with duties, hours, or pay; and paying additional expenses for work because of a disability.

Social Security Income’s PASS Program

An important Social Security Income (SSI) work incentive is called the “plan to achieve self-support” or “PASS” program. According to the Social Security Administration, the purpose of this plan is to help individuals get the items, services, or skills needed to reach their work goals, which ultimately should reduce their dependence on SSI. The PASS program allows individuals to set aside money for a number of things to assist with one’s work goals, and these earnings will not count toward one’s income calculations. Examples include transportation, tuition, child care, employment services, and more.

To set up a plan, it must be put in writing and Social Security must approve it. The information provided in this plan must include things such as one’s work goal, steps needed, items and services needed, and cost estimates. A local Social Security office can help with writing the plan if needed. They can also refer applicants to a vocational rehabilitation counselor to assist.

For individuals whose goal is to be self-employed, they will be required to include a detailed business plan with their application. This should include details such as the type of business; where it will be set up; hours of operation; and items needed to start the business. Social Security recommends that individuals consult with an expert – such as a representative from the Small Business Administration, a vocational counselor, or local banker, to help with writing a business plan.

For more information on these and other programs, please visit the Social Security’s website at www.socialsecurity.gov. Individuals wishing to speak with someone may call the Social Security office at **(800) 772-1213**. Hearing-impaired individuals may call their TTY number at **(800) 325-0778**.

The information provided in this section is from the publication, *Working While Disabled: How We Can Help*, published by the Social Security Administration in 2018.

Take Away and Follow Up: Making It Personal



You may want to ask yourself, “What dreams can be fulfilled?” Putting values into action allows for cutting out the things that are unimportant. Sometimes we treat all of our important responsibilities as urgent, forgetting that “important” is not always “urgent.” Discerning what to prioritize and what to let go of can be critical to a healthy quality of life. What are your feelings about change? Knowing can help determine ways to maximize healthy planning and abilities for coping well. Identifying a support system is important; create a team that can best support a healthy lifestyle.

Reflecting on the information presented in this booklet, are you on track to meet your goals for the future, both at work and personally? Reviewing the questions below could help identify some follow up to help make plans, keeping a proactive momentum toward the future. No need to be perfect! No need to have all the answers. This can be the beginning of an exciting journey to discover healthy new ways of functioning and increasing quality of life.

- What is flexible or inflexible about your work setting? Is this identifiable or do you need to make inquiries? _____

- Could small changes at work keep you employed and more satisfied or are you feeling the need for a larger change? _____

- Does your job satisfy needs beyond a paycheck? _____

- Have you noticed discomfort with your personal identity and/or roles? _____

- What are the symptoms that you feel are impinging on your work functions? _____

- Are these communicated to your neurologist? _____
- Do you need a referral to occupational therapy? _____
- Could some adjustments outside of work be helpful in improving your level of function? _____

- What personal assessment have you made or feedback have others provided to you about changes in your level of functioning, if at all? _____

- Are your financial needs met now? What are your financial concerns for the future and what actions are needed to make a plan? _____

- Depending on the climate and culture of your work setting, will you need additional resources to assist with requesting accommodations? (For example, discussion with neurologist, referrals to occupational therapist, or neurocognitive testing.) _____

- What is the status of your support system? _____

- Do you have mood symptoms that sometimes make you feel sad, or possibly even hopeless? * _____

* If feeling hopeless, please contact your health professional immediately; please also see the asterisk on page 10 for additional information.

Perhaps you have some new ideas or plans in mind. Below you can list a few items to focus on immediately and a few that will take more investigation. This is a plan for the long haul, so pace yourself, be kind, and call in the support you need to keep you moving in the direction you determine is best for you.

- List three short-term goals
 1. _____
 2. _____
 3. _____
- List three long-term goals
 1. _____
 2. _____
 3. _____

Resources for More Information

GOVERNMENT ACTS AND RIGHTS AT WORK

- For information on the **Americans with Disabilities Act (ADA)**, please visit www.ada.gov
- For information on the **United States Equal Employment Opportunity Commission (EEOC)**, please visit www.eeoc.gov
- For information on the **State Offices of Protection and Advocacy** for those with disabilities, please visit the **Administration for Community Living (ACL)** website at <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>
- For inquiries about your rights at work, please visit the **United States Department of Justice, Civil Rights Division**, at www.justice.gov/crt
- For information on the **United States Department of Labor Office of Disability Employment Policy (ODEP)**, and to locate multiple resources for people in the workforce with disabilities, please visit www.dol.gov/odep
- For information on the **Workforce Innovation and Opportunity Act (WIOA)**, which helps Americans, including youth and those with significant barriers to employment, to attain high-quality jobs and careers, please visit www.doleta.gov/wioa
- For information about the **Family and Medical Leave Act (FMLA)**, please visit www.dol.gov/general/topic/benefits-leave/fmla
- For information about the **Employee Retirement Income Security Act of 1974 (ERISA)**, a federal law that sets minimum standards for most pension and health plans, please visit www.dol.gov/general/topic/health-plans/erisa
- For the **National Employment Lawyers Association (NELA)**, please visit www.nela.org

Resources Continued...

JOB TRAINING AND EMPLOYMENT ASSISTANCE

- Your local **Office of Vocational Rehabilitation (VR)** offers services to people who need to reassess the type of work they are able to do if they need to change jobs due to disability. To find an office near you, please search online for “Office of Vocational Rehabilitation” followed by your state’s abbreviation.
- For local career counseling services, please visit the **National Career Development Association (NCDA)** at www.ncda.org/aws/NCDA/pt/sp/consumer_find and type in your zip code for a list of counselors in your area. (Please note that career counseling services can vary in price, so individuals may first try to check with the vocational rehabilitation office to see if they qualify for services directly, usually at no cost.)
- **Employment support services** for Social Security Disability beneficiaries who want to work may be found at www.choosework.ssa.gov
- To access a **blog with tips for people with disabilities looking to find long-term employment** if receiving Social Security Disability benefits and are ready to work, please visit www.choosework.ssa.gov/blog/a-path-to-work-for-people-with-disabilities
- To learn about resources for staying in the workforce, please visit the **Job Accommodation Network** at www.askjan.org
- A state listing for the **Employer Assistance and Resource Network (EARN)** on Disability Inclusion may be found at www.askearn.org/state-vocational-rehabilitation-agencies
- For information about **CareerOneStop**, a source sponsored by the United States Department of Labor for career exploration, training, and jobs, please visit www.careeronestop.org (Selecting “skills matcher,” under “toolkit,” is one of the many helpful options available.)
- For tools to assist with job searching, from resumes and cover letters to interview advice and job alerts, please visit **LiveCareer** at www.livecareer.com
- The **O*NET Program**, found at www.onetonline.org, is a source of occupational information and includes a database with descriptors on approximately 1,000 occupations.
- For **disability-friendly** job search sites, individuals may go to:
 - Getting Hired at www.gettinghired.com
 - Hire Disability Solutions at www.hireds.com
 - ABILITY Jobs at www.abilityjobs.com
- For the **Center for Independent Living** offices, please visit www.ilru.org/projects/cil-net/cil-center-and-association-directory