

Returning to Work

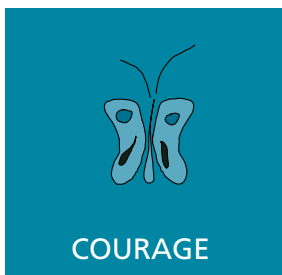
Is it Right for You?



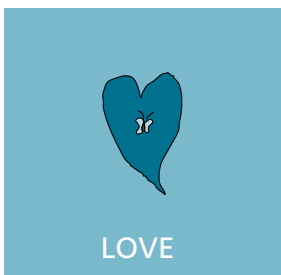
HOPE



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A Guide for
Brain Tumor Patients

*N***BT****F**
NATIONAL
BRAIN TUMOR
FOUNDATION

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Welcome

Many people with brain tumors can and do return to work, either at their former or a new, more suitable workplace. The challenges, socializing aspects, and financial incentives of a job can help you move ahead on the road to recovery.

Others have found that they are better served by focusing their energies on the recovery process. This is a very personal decision, for which there are no right or wrong conclusions.

If you are considering returning to your former job or starting a new one, this booklet can assist you in thinking about your options. It reviews your rights with respect to returning to work and suggests several strategies to ease your transition back into the workplace or to navigate the disability system.

It is our hope that this brochure will help you weigh your options and make the decision that is best for you and your family.

Returning to Work

CHALLENGES AND CONSIDERATIONS

YOUR DECISION to return to work should be based on your own capabilities and needs, the resources available to you, and consultation with your physician and a neuropsychologist. An important aspect of your decision to return to work is your physical and mental status. This will depend on the size, location, and type of tumor you have, as well as upon the type and intensity of treatment you have received. A neuropsychologist (and some trial and error) can help you anticipate the kinds of challenges you may have in a work environment. With the help of your medical team, employer and loved ones, you can develop strategies that will help you succeed in meeting the demands at work.

What Is a Neuropsychologist?

A neuropsychologist works with physicians and patients to understand the effects of injury and disease on mental abilities. The neuropsychologist conducts a series of tests to assess the patient's emotional state and cognitive (thinking) abilities. The tests examine areas like concentration, memory, problem solving, judgment, visual-spatial skills, and abstract thinking. This evaluation enables the neuropsychologist to spot the changes a tumor and treatment may have caused in the patient's mental capabilities and personality. A neurologist, family practitioner, hospital social worker, or rehabilitation center may be able to offer referrals for local neuropsychologists.

It may help to remember that the ability of a brain tumor patient to return to the workplace after diagnosis and treatment varies dramatically. Some patients are able to go back relatively quickly, with little or no loss in performance. Others cannot work at all, or can only handle a limited amount of their former responsibilities.

Challenges in Returning to Work

TALKING TO CO-WORKERS

The decision to tell others about your condition is a personal one. Some brain tumor patients feel that their health is a private matter while others find that letting their colleagues know about their brain tumor helps to make the work environment easier. For instance, if you do not reveal the existence of your condition to your co-workers, they may not understand why you may behave a little differently. To them, you may look and sound basically the same, regardless of how you actually feel. You may want to explore the best way to let people know about your brain tumor with a counselor, a social worker, or your supervisor. Attending a support group can also be a good way to hear from other patients about how they dealt with this issue.

INCREASED DIFFICULTY ON THE JOB

The biggest challenge you may face could be accepting the reality that your job may be more difficult than it used to be. You may become frustrated when tasks that used to be easy become hard. It may also be challenging for you to learn new skills as your job tasks change. It is important to return to work slowly and develop strategies for getting work done that can help you to deal with these changes.

Meeting the Challenge

If you are considering returning to work, you might want to think about different strategies you can use to maximize your success in the work environment. The following ideas may help you to prepare for your return to work or to adjust after you have started working.

CONSIDER RETRAINING

If necessary, seek retraining or other assistance before returning to work. Cognitive rehabilitation helps people regain as much of their abilities as possible. The training can improve concentration and communication skills; it can also help you process and organize information. In some cases, you may learn specific compensation techniques to make up for loss of functionality or ability. The training is usually conducted with the help of a neuropsychologist. Sometimes community colleges or independent living centers will offer classes in cognitive retraining. Check with a social worker or a local rehabilitation center for resources near you.

START SLOW

Many people want to go back to full-time work as quickly as possible. Be patient with yourself. Your brain may need time to heal, a process which typically takes 18-24 months. You may need time to recover physically and emotionally from your treatments, to undergo cognitive retraining, and to learn compensation techniques that can help you to function better. You may want to think about starting out part-time, or, if you are not returning to a previous job, volunteering a few days a week in order to assess your ability and energy level. A vocational rehabilitation center can be very beneficial in

making the transition back to work. You may also find it helpful to talk with other survivors who have returned to work.

COMMUNICATE YOUR SITUATION

You are not required to offer information about your diagnosis when applying for a job. However, you may want to discuss it with your supervisor when you begin work if you think you will need accommodations. While you should use your judgement to avoid discrimination, it can be helpful to be honest and upfront about your needs. Know your capabilities and limitations so you can minimize your own frustrations, and manage your employer's expectations by clearly specifying the tasks where you may need help.

MAKE YOUR ENVIRONMENT WORK FOR YOU

Set up your environment so that it is conducive to optimal performance. While each brain tumor patient has individual needs, some of these suggestions may help you in your work day:

- Keep a schedule to aid in remembering appointments, tasks, etc. Set your computer to provide automatic calendar reminders.
- Create checklists to keep track of the tasks you have completed and those still in progress.
- Use auditory or visual cues. Examples include tape-recorded messages to yourself, color-coded containers for specific items, and a pager or timer to remind you about tasks.
- Use office products to help keep objects in place and to improve work speed. Handy items include rubber finger tips and electric staplers.

PRACTICE RELEARNING

Relearn tasks through repetition, as well as through discussion and modeling. Learn one job or task thoroughly before going on to the next one. Repeat instructions to the person giving them to you. If you get an assignment in writing, ask someone to review it with you in order to clarify that you understand everything.

PRIORITIZE WORK

Learn your medication schedule and how it affects your energy level. For some patients, focusing on the more difficult tasks first can help to avoid the effects of fatigue later in the day. For other patients, the mornings may be the most difficult. You should try to set your work schedule accordingly.

Your Rights When Returning to Work

The federal Americans with Disabilities Act of 1990 (ADA) prevents job discrimination for individuals with a qualifying disability. The law applies only to employers with 15 or more employees. Your state may also have laws against job discrimination. If you can perform the essential duties of a job:

- The employer cannot discriminate against you in hiring.
- The employer must make reasonable accommodations that will allow you to perform the job, unless doing so would cause an undue hardship on the employer.

Despite most employers' best intentions, abuses and discrimination may occur. If you feel that you have been discriminated against, contact the Equal Employment Opportunity Commission (EEOC) at 800.669.4000.

UNDERSTAND YOUR DISABILITY AND ADAPT

Don't hesitate to ask for assistance. Find out about which resources your company offers, as well as other resources in the community.

REQUEST NEEDED ACCOMMODATIONS

You can work with your employer to make reasonable accommodations in the workplace. Reasonable accommodations are required under the Americans with Disabilities Act of 1990 (ADA), but only if your employer is aware of your disability. Reasonable accommodations may include adaptive or assistive technology, physical changes to the workplace that help you to deal with any physical impairment, or changes in the environment or job structure that make dealing with a cognitive impairment easier. Your employer may be able to:

- Develop a job-sharing situation.
- Provide (minimal) assistance from a co-worker, supervisor or personal care attendant.
- Spread out work tasks.
- Modify your work schedule. For instance, if you are experiencing fatigue, consider flexible hours or arrange to do strenuous work early in the day. For some individuals, part-time or early evening hours might be ideal.
- Restructure meetings to help with inattentiveness. Request more one-on-one time with your supervisor, schedule more frequent breaks, or try using cue cards and other visual aids.
- Reassign you to a vacant position that is more suited to your current abilities.
- Provide a temporary job coach to help train you.
- Provide additional unpaid leave for required medical treatment.

Deciding Not to Return to Work

NAVIGATING DISABILITY PROGRAMS

IF YOU CANNOT return to work, you may be eligible for various benefit programs, either on a temporary or permanent basis. Applying to the programs can be complicated, so you may want to enlist the help of a friend or loved one. A hospital social worker or local social service agency (such as an independent living center) can provide more detailed information and valuable assistance with the application process. Some organizations have a trained benefits counselor who can help you understand your options and how to access coverage.

Social Security Administration

The Social Security Administration (SSA) offers two financial assistance programs for people who qualify as “disabled”: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

Both SSDI and SSI define disability in the same way. According to the official definition, a person with a disability is someone who is unable

Important Note

These programs and the information on the following pages are subject to change. Always be sure to request a copy of the most current eligibility requirements and benefits.

to perform any “substantial gainful activity” (work) because of a mental or physical impairment. The impairment must be medically documented **AND** either considered terminal or expected to keep the person from working for at least 12 months.

Substantial Gainful Activity (SGA) refers to the ability to perform work (for pay) and earn a certain dollar amount, which is determined each year by the federal government. For instance, if the federal government determines the SGA is \$900 per month, then a person who earns over this amount is not considered disabled.

Medical documentation must support any claims of impairment. Medical evidence can include documented symptoms, medical records, and a physician’s certification. The impairment caused by brain tumors is not always outwardly visible, which can make it harder to demonstrate a disability. You might consider keeping a journal of your symptoms and how they affect your functioning. For instance, severe fatigue may affect your ability to perform work. Ask your doctor to include your journal in your medical record as supporting evidence of your impairment.

You can request a “Disability Starter Kit” with answers to frequently asked questions and information about the specific documents you will need from the Social Security Administration at **800.772.1213** or online at **www.ssa.gov**.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

Social Security Disability Insurance (SSDI) provides wage replacement income to eligible individuals. *It is not based on need*, but rather on past contributions to the Social Security system (known as credits). Credits are earned by working in a job where Social Security taxes (FICA) are withheld

from your paycheck, or by paying self-employment taxes when you work as a self-employed person.

Qualifying for SSDI Benefits

To qualify for SSDI benefits, you must

- Be a legal U.S. resident
- Be disabled according to SSA's rules (see page 9),
AND
- Have earned a minimum number of credits (have paid a minimum amount into the Social Security system) within the appropriate time period before becoming disabled. The number of credits you need depends on your age when you became disabled. Contact the Social Security Administration office to find out the number of qualifying credits based on age.

If you are applying for coverage for a minor, ask your Social Security Administration office for special requirements for disabled minors.

Applying for SSDI Benefits

You should apply as soon as you become disabled and are no longer working to allow plenty of time for your application to be processed. SSDI benefits are payable after a mandatory waiting period.

You may begin the process by contacting the Social Security Administration by telephone at **800.772.1213** (Monday–Friday) to schedule a telephone or office appointment. If an office or telephone appointment is not possible, you can request a home or hospital visit. If you schedule an office appointment, find out which office is closest to your home. In addition, make sure to ask which documents, such as a birth certificate, Social Security card, etc., you will need for your appointment. It is helpful to bring contact information for

your medical team, the names and dosage of your medications, and any medical records already in your possession.

SUPPLEMENTAL SECURITY INCOME (SSI)

Supplemental Security Income (SSI) is a program *based on need* that provides monthly income support to disabled individuals. It is not necessary to have paid Social Security taxes (to earn “credits”) to receive the benefits, but you must meet the financial and other requirements to qualify.

Qualifying for SSI

You may be eligible for SSI if you are disabled **AND** have financial need. Financial need is determined by having limited income and limited assets (house, car, etc.). You must also meet the other requirements, such as residency and participation in other benefit programs. For information regarding specific requirements, call **800.772.1213** or visit their website at **www.ssa.gov**.

Applying for SSI

Apply as soon as you become disabled and are no longer working to allow plenty of time to process your application. (Unlike SSDI, there is no waiting period for SSI, although it takes about four months or longer for eligibility to be determined.)

You may begin the process by contacting the Social Security Administration at **800.772.1213** to schedule a telephone or office appointment. If a telephone or office appointment is not possible, you can request a home or hospital visit. If you schedule an office appointment, find out which office is closest to your home. In addition, make sure to ask which documents, such as a birth certificate, Social Security card, etc., you will need for your appointment.

State Disability Insurance Programs

Currently only certain states provide a state disability insurance program. Contact your local hospital social worker or check your local phone listings under “State Programs” to ask about additional information on eligibility requirements and benefits.

Medicare

Medicare is a *federal health insurance program* for the elderly and/or disabled.

QUALIFYING FOR MEDICARE

To qualify for Medicare, you must

- Be 65 years or older (although you may qualify at any age if you have kidney failure or are blind) **OR**
- Have been receiving Social Security Disability Insurance (SSDI) benefits for 24 months.

APPLYING FOR MEDICARE

Contact the Social Security Administration office at **800.772.1213**. If you have been receiving SSDI (see page 10) for two years, you should automatically be sent information about applying for Medicare, although we recommend requesting this information yourself.

Medicaid

Medicaid is a *state-administered health insurance program* for low-income and needy individuals. It is jointly funded by the state and federal govern-

ments. Each state determines its own requirements, services, and whether certain eligibility groups (such as the blind or disabled) are covered. In most states, eligibility is linked to the financial requirements of the federal Supplemental Security Income (SSI) program (see page 12). Check with your hospital social worker or call your local Department of Social Services to receive more information about guidelines for your state.

United States Department of Veterans Affairs (VA) Programs

QUALIFYING FOR VA BENEFITS

If you are a disabled veteran you may be entitled to a variety of benefits, e.g., pension for non-service-related disabilities, compensation for service-connected disabilities, vocational rehabilitation, readjustment counseling, medical and dental care, home loan guarantees, educational benefits, and burial costs.

APPLYING FOR VA BENEFITS

For more information regarding eligibility and how to apply for benefits, you can call the U.S. Department of Veterans Affairs at **800.827.1000**.

Resources

A variety of additional resources can assist you during your return to work. A partial listing is provided below. Check in your local area for other organizations that might be able to assist you.

General Resources

National Brain Tumor Foundation

800.934.2873 • www.braintumor.org

Provides information and resources to brain tumor patients and family members.

The Brain Injury Association, Inc.

800.444.6443 • www.biausa.org

Provides information, education and support to those affected by traumatic brain injury.

Cancer Legal Resource Center

866.843.2572 • www.disabilityrightslegalcenter.org

National hotline that provides free information on cancer-related legal issues.

DisabilityInfo.Gov

800.333.4636 • www.disabilityinfo.gov

Federal website with information for people with disabilities.

Equal Employment Opportunity Commission

800.669.4000 • www.eeoc.gov

Federal agency that handles employment discrimination complaints.

Family Caregiver Alliance

800.445.8106 • www.caregiver.org

Provides education, information and support for family caregivers.

Job Accommodation Network

800.526.7234 • <http://janweb.icdi.wvu.edu>
Provides free consultations about workplace accommodations and increasing employability.

National Coalition for Cancer Survivorship

877.622.7937 • www.canceradvocacy.org
Specializes in advocacy and assistance with employment and other survivorship issues.

Patient Advocate Foundation

800.532.5274 • www.patientadvocate.org
Provides assistance with finance-related issues, including disability claims and employment rights.

People Living with Cancer

888.651.3038 • www.plwc.org
Provides information on survivorship issues.

The United Way

www.national.unitedway.org
Has resource directories that list a wide range of resource agencies.

Rehabilitation Services Administration

The Office of Special Education and Rehabilitative Services provides services to individuals with disabilities to help maximize employment, economic self-sufficiency, independence, and integration into society.

You can call the **Rehabilitation Services Administration** at 202.245.7488 or visit www.ed.gov to obtain information on your state's Department of Rehabilitation office.

Publications

Be Prepared: The Complete Financial, Legal, and Practical Guide for Living with a Life-Challenging Condition by David S. Landay.

Comprehensive, easy-to-use guidebook on practical and legal issues. St. Martin's, 1998.

The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer by Michael

Feuerstein and Patricia Findley. Provides a practical action plan for guiding survivors through diagnosis and life after treatment. Marlowe & Company, 2006.

Working it Out: Your Employment Rights as a Cancer Survivor published by the National

Coalition for Cancer Survivorship. Call 877.622.7937 to receive a copy of this publication.

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The National Brain Tumor Foundation

The National Brain Tumor Foundation is a nationwide non-profit organization that serves people whose lives are affected by brain tumors. We are dedicated to promoting a cure for brain tumors, improving the quality of life and giving hope to the brain tumor community by funding meaningful research and providing patient resources, timely information and education. Our services to patients, their loved ones, and health professionals include:

- Toll-free Patient Information Line at **800.934.2873**
- Medical Information Nurse
- Quarterly newsletter, comprehensive website at **www.braintumor.org**, and other publications
- Patient and Caregiver Support Network via phone and e-mail
- National caregiver training workshops
- Teleconferences and web conferences
- Patient Help Fund financial assistance program

The information in this brochure is subject to change. The reader is advised that information obtained from a physician should be considered more up-to-date and accurate than the information in the brochure and that this brochure does not and cannot purport to address facts and circumstances particular to any patient. This is something that can only be done by the patient's physician. Sponsorship of this brochure does not imply the National Brain Tumor Foundation's endorsement or recommendation of any particular form or forms of therapy, regimen, or behavior. The information in this brochure is not meant to be legal advice or replace the advice of an attorney.



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