

RETURNING TO WORK

*Strategies for
Brain Tumor Patients*



**NATIONAL BRAIN TUMOR
FOUNDATION**

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INFORMATION LINE: 800.934.CURE

RETURNING TO WORK

Strategies for Brain Tumor Patients

This brochure is based, in part, on a presentation by Jay Katz, Director of Rehabilitation and Social Services, Recreation Center for the Handicapped, Inc., San Francisco, at the Fourth Biennial National Brain Tumor Conference, sponsored by the National Brain Tumor Foundation. Special thanks are owed to Helen Pellegrin, Ph.D., and Elizabeth Stevenson for their comments and suggestions.

This pamphlet is dedicated to the memory of Karen O. Brownstein, who conceived and authored the first patient education materials for the National Brain Tumor Foundation.

The National Brain Tumor Foundation, a non-profit organization established in 1981, provides supportive services to brain tumor patients and their families as well as raises funds for research. For more information please contact us at:

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MANY PEOPLE WITH BRAIN TUMORS CAN and do return to work. The challenges, socializing aspects, and financial incentives of a job can help you move ahead on the road to recovery. 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.



How to Decide to Return to Work

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. With the aid of a neuropsychologist (and with some trial and error), you can try to anticipate the kinds of problems you may have in a work

environment, and learn to compensate for any weaknesses you have identified.

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

Telling Co-Workers about Your Brain Tumor

The decision to tell others about your condition is a hard one and 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

What is a Neuropsychologist?

A neuropsychologist works with physicians and patients to understand the effects of injury and disease on mental abilities. The neuropsychologist, who usually has a Ph.D. in psychology, conducts a series of tests to assess the patient's emotional state, daily behavior and cognitive (perceptive) abilities. This evaluation enables the neuropsychologist to spot the changes a tumor 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.

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 in the Job

Perhaps the biggest challenge you face is 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. And if your job tasks change, this can cause an added layer of frustration and difficulty, because it may be very challenging for you to learn new skills. It is important to return to work slowly and learn to acquire skills that can help you to deal with these changes. This booklet can help you to develop a strategy for addressing some of these difficulties.



Meeting the Challenge

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

Strategies When Returning to Work

If necessary, seek retraining or other assistance before returning to work.

Cognitive retraining, usually with the help of a neuropsychologist, can improve concentration and communication skills; it can also help you process and organize information. In some cases, specific compensation techniques can help to make up for any loss of functionality.

When possible, start slow.

Many patients make the mistake of going back to full-time work too quickly. Your brain may need time to heal, which typically takes 18 to 24 months. Or you may need time to recover physically and emotionally from your treatments and to undergo cognitive retraining (and/or 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.

When accepting a new job (or going back to an old one), be honest and up front about your needs and expectations. Make sure your employer's expectations are also realistic.

It is important for you to know your own capabilities and limitations so that you can minimize your own frustrations. It is equally critical that you manage your employer's expectations. You can minimize your stress (and make sure you keep your job) by working with your employer to modify your responsibilities as needed.

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 lists or work logs to aid in remembering appointments, tasks, etc.
- Create checklists to keep track of the tasks you have completed and the tasks you are working on.
- Use individual auditory or visual cues (such as tape recorded messages to yourself, color-coded containers for specific items, charts with diagrams or pictures, or a vibrating pager or timer to remind you about tasks).
- Use materials to keep objects in place or to improve work speed. Examples would include an electric stapler, rubber band holders, rubber finger tips, laminated work materials, and specialized matting.

Relearn tasks through repetition, as well as through discussion and modeling.

Learn one job or task thoroughly before going onto the next one. Repeat instructions to the person giving it 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

Get to know your medication schedule and how it effects 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 and set your work schedule accordingly.

Understand your disability and adapt.

Don't be hesitant to ask for assistance. Find out what resources your company has as well as other resources in the community.

Work with your employer to make reasonable accommodations in the workplace.

Reasonable accommodations are required under the Americans with Disabilities Act of 1990 (ADA). Reasonable accommodations may be physical changes to the work place that help you to deal with any physical impairment, or may be changes in the environment or job structure that make dealing with a cognitive impairment easier.

Your Rights When Returning to Work

The Americans with Disabilities Act of 1990 (ADA) prevents job discrimination for any disabled individual (including those with brain tumors). 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.

Despite the best intentions of most employers, 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.



Examples of Changes in Job Structure

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 work schedules; for instance, if you are suffering from fatigue, perhaps you could try 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 (by providing more one-on-one time with a supervisor, using cue cards or other visual aids, and allowing more frequent breaks).
- Reorganize work-time routines.
- Reassign you to a vacant position if you are unable to perform essential functions of your previous job.
- Provide a temporary job coach to help train you.
- Provide additional unpaid leave for required medical treatment.

IF YOU CAN'T GO BACK TO WORK

*A Note on Disability Programs**

If you cannot return to work, you may be eligible for various benefit programs, either on a temporary or permanent basis. A hospital social worker or local social service agency can provide more detailed information and possible assistance with the application process.

Following is a brief description of programs that may be of interest to you.

Important Note

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

Medicaid

Medicaid is a joint federally and state funded program that provides medical insurance to eligible persons. Medicaid is currently linked to SSI. Due to the joint funding, each state has different requirements and programs; call your local Department of Social Services to receive more information or check with your hospital social worker.

**This disability information has been adapted/updated with permission from the 1995-1996 San Francisco AIDS Foundation Resource Guide.*

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
- ✓ you have been receiving Social Security Disability (SSDI/SSA) benefits for 24 months.

Applying for Medicare

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

Social Security Administration

The Social Security Administration offers two programs for people who are disabled: Social Security Disability (known as SSA or SSDI) and Supplemental Security Income (known as SSI). Both programs define “disability” as “a medically determinable impairment which results in marked and severe functional limitations and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”

Social Security Disability (SSA, SSDI)

Social Security Disability is not need-based, but is rather based on your past contributions to the Social Security system.

QUALIFYING FOR SSA BENEFITS

To qualify for SSA benefits,

- ✓ you must be disabled (see definition on page 10), and
- ✓ if you are over 31, you must also have paid a minimum amount into the Social Security system during five of the last ten years before becoming disabled; if you are under 31, this requirement is lower. Paying into the system means that you must have worked in a job or jobs where Social Security taxes (FICA) were withheld from your paycheck, or you must have worked as a self-employed person who paid self-employment taxes.

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

APPLYING FOR SSA 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. SSA benefits are payable after a mandatory waiting period, so you should apply for benefits during the month following your last day of work.

You may begin the process by contacting SSA by telephone at 800.772.1213 (Monday–Friday) to schedule a telephone or office appointment. If you are bedridden and 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.

Supplemental Security Income (SSI)

Supplemental Security Income is a need-based program; you do not have to have paid Social Security taxes (FICA).

QUALIFYING FOR SSI

If you are disabled AND have financial needs, you may be eligible if you meet the specific requirements for SSI. For information regarding requirements, call your Social Security office at 800.772.1213 to get a copy of the pamphlet “A Desktop Guide to SSI Eligibility Requirements,” published by the Social Security Administration, or visit their Web site at www.ssa.gov to view most all of their publications.

APPLYING FOR SSI

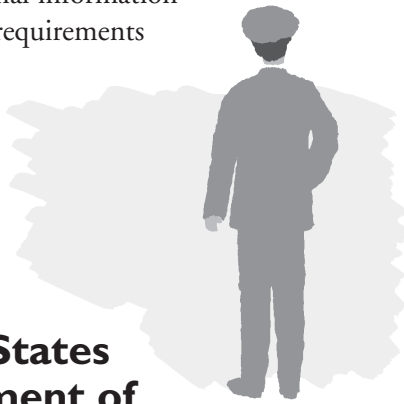
Apply as soon as you become disabled and are no longer working to allow plenty of time for your application to be processed. (Unlike SSDI/SSA, there is no waiting period for SSI, although it takes about 4 months or longer for eligibility to be determined.)

You may begin the process by contacting the Social Security office at the number provided above to schedule a telephone or office appointment. If you are bedridden and 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 Program (SDI)

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.



United States Department of Veterans Affairs 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.

IN CLOSING

Many survivors of brain tumors have been able to return to either their former or a new, more suitable workplace. 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 answers. NBTF hopes this pamphlet helps you weigh your options and make the decision that is best for you and your family.

Resources to Assist You in Your Return to Work

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

FAMILY CAREGIVER ALLIANCE: www.caregiver.org

NATIONAL BRAIN TUMOR FOUNDATION:
1.800.934.CURE—Provides information and resources to brain tumor patients and family members. www.braintumor.org

THE BRAIN INJURY ASSOCIATION, INC.:
703.236.6000 www.biausa.org

NATIONAL COUNCIL ON INDEPENDENT LIVING:
Call 703.525.3406 for a listing of state-wide centers or visit their Web site at www.ncil.org.

REHABILITATION SERVICES ADMINISTRATION:
Department of Rehabilitation—Each state has a department of rehabilitation that provides services to individuals with disabilities to help maximize employment, economic self-sufficiency, independence, and inclusion and integrating into society.

You can call the REHABILITATION SERVICES ADMINISTRATION at 202.205.5482 and ask for the number of your state's Department of Rehabilitation office.

THE UNITED WAY has resource directories that list a wide range of resource agencies.



Publications

Working it Out: Your Employment Rights as a Cancer Survivor published by the National Coalition for Cancer Survivorship. Call 301.650.8868 to receive a copy of this publication.

Newsletters: *Region IX Rehabilitation Network* 1.800.727.5232 They publish a newsletter and are an excellent source of information about supported employment, new regulations, etc.

Triumph: Getting back to Normal when you have Cancer by Marion E. Morra. Has a section on “Money Matters” and “Major Information Sources” that is up-to-date and invaluable.

Patient Information Line:
1.800.934.CURE

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.