Practical Considerations

There’s a lot we can do, so I’m ready to fight and keep fighting with Darren. We’re in this together.

— Carrmen, caregiver
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Practical Considerations

There’s so much more to consider than treatment and recovery. There’s work, finances, family, and the future. What’s really important to you and what isn’t? What do you need to do now and what can you do later?

THING TO REMEMBER

-> Going back to work is a practical and personal decision.

-> Review your goals, perspective or abilities after a brain tumor diagnosis.

-> There are federal laws and supports that can protect someone with cancer from losing their job due to new disabilities.

-> Aim to manage medical costs in an organized and informed way.

-> Making practical end-of-life plans helps everyone, whether healthy or ill. If you don’t already have a will and advanced directives in place, consider making these plans now.

-> You can gain control over the future and make plans that give everyone involved a sense of peace.

-> Caregiving is a difficult job. People who need help should be aware of how their caregiver is coping and aim to find balance with everyone’s changing role.
There is not one “right” answer about working full-time, part-time, or not at all during or after treatment. This is a practical decision, based on your needs, abilities, and personal preferences. Some people make a complete recovery from their brain tumor while others have lasting effects. It isn’t always possible to know how things will turn out.

Your health care team can suggest how your treatment and prognosis might affect your ability to work, so it can help to talk with them about your job and your work-based priorities through treatment and recovery. Consider what’s best for you at each point in your experience.

If you hold a job where your mental skills are important, or where your strength is needed for heavy machinery, you may not be able to continue at the same level. This can feel devastating.

Sometimes an employer can arrange for you to take on another role until you are fully better, or you may ask to go back to work part-time until you regain your strength.

It will take time to come to terms with career changes, and to determine what you would like to do next. If you think you’ll need to choose a different type of work or need financial guidance, then it may be useful to see a social worker or counselor for help.

**THINGS TO CONSIDER ABOUT WORK**

- Do I enjoy my work and/or find it a welcome distraction?
- Have my career priorities changed?
- What does my health care team recommend?
- Can I complete my work functions while in treatment?
- What should I expect about my abilities and side effects after treatment?
- How much sick leave do I have?
- Am I eligible for the Family Medical Leave Act if I need to take time off?
- Does my state offer short-term disability insurance? Or can I receive disability insurance payments through my employer or private insurance?
- Will I qualify for long-term Social Security Disability Insurance (SSDI)? If so, do I have savings to carry me through the 5-6 month waiting period?
- If I decide to stop work temporarily, how will this affect me and others?
- If I decide to stop work, what will I need to do to keep health insurance?
How much you tell an employer about your health is an individual decision. Some people find it helpful to tell their employers about their diagnosis, while others wish to keep it private. Do whatever feels right to you.

An advantage to letting your boss know is that it may be less stressful when you need to rearrange your work schedule or miss a substantial amount of time at work. As long as you can do your work, there are laws to protect you from discrimination due to a brain tumor diagnosis.

No matter what type of relationship you have with your boss, it’s good practice to keep records of your conversations regarding your diagnosis. If you request accommodations for your work, ask for this in writing. You may also want to make a copy of any recent performance reviews and any positive statements about your work.

Make note of anything that could indicate discrimination. In the unlikely event that you have problems with your employer in the future, careful records can prove invaluable in your defense. Your state’s fair employment agency can help you with additional questions.

If you go back to work with a scar on your head, people are going to question not only how you’re doing, but also your work product. You have the burden of proving that you’re healthy and proving that you’re competent. I think that takes a toll on you… especially because things aren’t exactly the same.

— Archie, patient
Employment Laws and Financial Support

AMERICANS WITH DISABILITIES ACT (ADA)
The ADA is a federal law that protects workers with a disability (including a brain tumor and/or effects of treatment) against discrimination as long as a worker can complete his/her job. The law requires that employers make reasonable accommodations so people with disabilities can function. This might include modifying a work schedule or making the physical workplace accessible with things like hand rails or tools for hearing loss. You can ask your medical team about accommodations if you need them.

FAMILY AND MEDICAL LEAVE ACT (FMLA)
The FMLA entitles eligible employees to take up to 12 workweeks of unpaid, job and benefit-protected leave in a 12-month period for specified family and medical reasons. FMLA covers time to care for a spouse, parent or minor child with a serious health condition, or to take personal medical leave. This law only applies when an employer has 50 or more people employed within 75 miles, and when a worker has worked for at least 1,250 hours during the past year.

The law does say that when leave is needed for planned medical treatment, the employee must make a reasonable effort to schedule treatment in a way that won’t disrupt the employer’s operation.

If you have questions about these and other benefits, such as Employer Sponsored Insurance provided by your employer, you should discuss this specifically with your boss and/or your human resources department.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)
SSDI is a federal program through the Social Security Administration that provides a monthly payment to people who have worked for a sufficient period of time, paid Social Security taxes, and are deemed “disabled” by Social Security. In addition to the monthly check (paid after a waiting period), after two years of receiving this monthly benefit, SSDI recipients are also entitled to Medicare.

Many people diagnosed with mid to late-stage brain cancer qualify for SSDI. If you are not working and you think you might want to apply, it is helpful to start sooner rather than later. The Social Security Disability application process can take more than 100 days; and a year or longer if you have to appeal.

SUPPLEMENTAL SECURITY INSURANCE (SSI)
If you have a very low income and minimal savings and assets you may qualify for benefits. These would begin immediately. You would be able to receive monthly payments during the SSDI waiting period, if you qualify.

You may also qualify for the Supplemental Nutrition Assistance Program (SNAP, formerly Food Stamps) and Medicaid. Medicaid can be a welcome relief, if you are struggling to pay for private medical insurance and qualify. The social worker or financial counselor at your treatment facility can provide more information.

For more information about co-pay assistance programs, see p. 70.

To apply for SSDI or SSI: call 1-800-772-1213; go online to www.socialsecurity.gov/disability.
The very first question you may ask yourself about managing the financial aspects of your diagnosis is: “Am I able to coordinate the financial piece of my medical care right now?” If you answer “No,” perhaps you can ask a friend or family member to do this for you. Insurance companies can sometimes assign a caseworker to help you navigate insurance benefits and costs. Often, people can use some help.

Try to anticipate and plan for the many costs that can accompany a brain tumor diagnosis. These costs can include special medications and supplements not covered by insurance, child care, elder care, transportation, parking, food delivery – in some cases, even oral chemotherapy. Though this can seem overwhelming (especially with concerns about your health), it’s helpful to feel like you have a plan in place to manage the costs of care.

**MANAGING MEDICAL COSTS**

**COPING WITH THE COST OF CARE**

*Frankly Speaking About Cancer: Coping with the Cost of Care* is a free publication by the Cancer Support Community that can help guide you through the financial impact of medical care.

Order this booklet through [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) or by calling 1-888-793-9355

**PRACTICAL TIPS FOR COPING WITH THE COST OF CARE**

- Get a notebook to record your expenses, conversations with the insurance company, medical appointments, and other pertinent information (date, time and who helped with what).
- Pick a certain day to be ‘health care bill day.’ Use this allotted time to work on the task of keeping things organized. This will prevent it from becoming overwhelming.
- Get an accordion folder to help you file papers so you can find them easily, or ask for electronic billing information so you can create electronic files you can access.
- Identify one spot where you and someone you trust can easily access bills, paperwork, and notes.
CONSIDERING PRIVATE HOME CARE AND LONG TERM CARE

Private duty or custodial care includes services such as having someone drive to your home to fix meals or drive you to medical appointments. When this type of help is needed, it’s good to know what costs are involved. Unlike home health care with skilled nurses, private duty or companion care are usually not covered by health insurance.

Similarly, long-term care is not typically covered by health insurance. Long-term care involves extended care at a nursing home or other specialized facility for a longer period of time than rehabilitation care.

QUESTIONS FOR YOUR HEALTH CARE TEAM

- What local organizations provide low-cost or free private duty care or other services?
- Should I plan financially for long-term medical care such as a nursing home or hospice care?
- Who can help me understand my state’s Medicaid rules (www.medicaid.gov) for long-term care and my eligibility?

QUESTIONS ABOUT LONG-TERM CARE

- Are private duty care and long-term care covered under my health insurance policy? If not, can I purchase this additional coverage now?
- Do you have a special rate for people paying out-of-pocket?
It’s helpful for all adults, regardless of their current health status, to prepare for the future by having their affairs in order. Ensuring that legal documents exist, including a will, living will, and advanced directives will help maintain your sense of control and provide you and your family with guidance.

It helps to talk with those closest to you about questions like: “At what point is it time to stop active treatment?” and “How does what I leave behind affect my family’s future?” These are difficult discussions, but it’s important to provide direction for those closest to us, and prevent problems later.

There are several important documents to consider for advanced care planning. If you have questions, please speak with your doctor, nurse, or social worker.

**Living Will**
The living will is a legal document that states whether or not we would like to be placed on life support if our bodies cannot survive without such “heroic” intervention. This information should be given to doctors and family members when we are still actively making our own decisions. Most doctors have a standardized state form available. Once completed, all people involved should have a copy.

**Health Care Proxy or Medical Power of Attorney**
This is a legal document that allows us to appoint a trusted person to make medical decisions for us if we cannot make them for ourselves. In many states, the person you appoint (your Medical Power of Attorney) is able to speak on your behalf if you are not able. It is important that this person knows your wishes and is willing to take responsibility.

**Financial Power of Attorney**
A trusted person is legally named Financial Power of Attorney to make financial decisions on our behalf when we are incapable or otherwise desire assistance with money and finances. If you have to manage multiple bank accounts, know that each bank or financial institution may require you to file separate forms of proof.

**Will**
The Will is a legal document that defines what we want to do with our property, money, and other possessions (including children) after we die. Guardianship may be a key element of a Will. If a person has no written Will, the laws of the state can determine how wealth and children are passed along to family members.

These documents can be created independently (you can look online to find sample forms for you and your family to fill-out and keep on record), or formally with a lawyer.
DEATH AND DYING

When you are diagnosed with a potentially life threatening illness, it’s common to think about death. It’s normal for people diagnosed with a serious brain tumor to want to discuss the possibility of death and to anticipate what they might want or need in the weeks, months or years ahead.

On the other hand, individuals might not want to discuss this, because it’s difficult or sad. These discussions can be important and powerful parts of the coping process.

Talking openly about your feelings and desires can help you and your family to maintain control over this time, and provide you the opportunity to accomplish certain goals or put closure to matters. It’s valuable to feel prepared for whatever lies ahead. Remember that a social worker or professional counselor is always someone who can help ease and enlighten these discussions.

YOUR CAREGIVERS

As a person receiving help, you may resent the need after being able bodied, or feel terrible guilt for being a burden on someone you love. Perhaps you don’t even realize that you are using a loved one’s time. It’s valuable to look at how caring for you is affecting your loved one, from their eyes. Living with someone who has a serious disease is not easy.

Most caregivers are happy to help and don’t want you to feel guilty about what they can provide. It’s important to talk honestly with your caregiver, and get a sense of when and how they could use a break. Try to express your appreciation when you can. There are many things that can help your caregiver cope with their new role — Chapter 7 offers some guidance.

When I was diagnosed, I wanted to know “what did I do wrong?” I realize the answer is “Nothing”... but still, that’s infuriating!

— Tony, patient
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**CANCER SUPPORT COMMUNITY’S FRANKLY SPEAKING ABOUT CANCER SERIES**

Cancer Support Community's *Frankly Speaking About Cancer: Brain Tumors* program is part of a national education program that provides support, education, and hope to people affected by cancer and their loved ones.

*Frankly Speaking About Cancer* booklets feature information about treatment options, how to manage side effects, the social and emotional challenges of the diagnosis, and survivorship issues.

For more information about this program, the *Frankly Speaking About Cancer* series or Cancer Support Community, please visit our website at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) or call us toll-free at 1-888-793-9355.
Cancer Support Community and the National Brain Tumor Society together with our partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or another health care professional to answer questions and learn more.

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