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Preface

In 2010, the Brain Injury Alliance of Kentucky and the Michael Quinlan Brain Tumor Foundation merged to better serve the needs of persons with brain tumors and/or cancer. Even though a tumor or cancer diagnosis has its own unique set of problems, you may have neurological issues that are consistent with a brain injury. Therefore, you may also be eligible for some services that are for persons with brain injury. We want you and your family to have the tools you need for your total treatment: physically, mentally and emotionally.

The articles in this publication seek to provide you with some effective strategies in coping with your diagnosis. The goal of this information is to equip you and your family with some tools that have been proven helpful to others who have had a brain tumor.

The companion to this booklet is the BIAK Resource Journal. In it you will find information about how the brain works and what to expect from rehabilitation. The resource section of the BIAK Resource Journal will be referred to when there are resources that are available to persons with the diagnosis of brain tumor. The resources provided in this booklet are those for persons with a brain tumor and/or cancer. If you did not receive a copy of the BIAK Resource Journal, please contact us and one will be sent to you at no charge. You may also access the BIAK Resource Journal on-line at www.biak.us.

We endeavor to make sure the information in this Journal is current and up-to-date. However, if you see that a resource is no longer available, or you learn of a new resource, please let us know and we can correct, add or update the information to keep this journal current.

Sincerely,

Eddie Reynolds, Editor
Only those who have been in your place have any idea of how you are feeling right now and there is no “right” response to the news of a cancer diagnosis. However, others have successfully coped with this, or a similar diagnosis. Their experience reveals some common factors that have proven to be helpful to both the patient and the family. This section is provided to help you be the best patient possible in your struggle with your diagnosis.

Learning About Your Diagnosis and Treatment Options

There are over 120 different types of brain tumors and they fall in two broad camps: primary and metastatic. Primary brain tumors originate in the brain and often there is no known cause for these tumors. Metastatic tumors are tumors that began in one part of the body and have now spread to the brain. Tumors may also be benign or malignant. Benign tumors are tumors that do not spread or cause serious injury. Malignant tumors are those that grow in rapid, uncontrolled ways and are much more serious.

When you meet with your doctor, be sure to ask about the type of tumor you have, where it is located and if they know what grade it is. Tumors are graded on a scale from one to four, with one being the least aggressive and four being the most aggressive tumor. You will also be able to get reliable information about your particular tumor from the American Brain Tumor Association on-line at www.abta.org.

Both benign and malignant tumors in the brain take up space in your skull and interfere with normal brain function. This can cause damage by exerting pressure on the brain, causing the brain to shift, invading brain tissue and damaging nerves within the brain.

The location of your tumor is important, each area of the brain performs functions that make daily living possible. Refer to the article, The Brain: How it Works and How it is Injured on page 8 in the BIAK Resource Journal. This article explains the major areas of the brain and the function of each area. Understanding the type of tumor you have and its location will help you be aware of what you can expect and what your options are for treatment. Your doctor will be glad to explain all of this to you and your family.

No doubt you will want to learn more about the treatment your doctor recommends. The common recommendations for brain tumors are: observation, surgery, radiation and/or chemotherapy. It is helpful to know the reasons, benefits and risks of each of these treatments. Your doctor and treatment team can help you prepare for these treatments, explain the reason for their decision, and present you with any available options.

- **Observation.** Sometimes a mass or tumor is too small to operate on, is in a location that is not readily treated by surgery or other treatment, or may be considered “low risk” and your physician may recommend watching to see if there are any changes in symptoms or neurological functioning. You may need scans to monitor the tumor from time to time to see if there are no changes in the tumor.

- **Surgery.** Surgery to determine the diagnosis of the tumor is called a biopsy. Biopsies may be stereotactic or open. Stereotactic biopsies are the least invasive and involve machines that specifically localize the tumor and use a needle to withdraw a small tissue sample. The open biopsy
involves a larger opening to remove a tissue sample to see if it is cancerous or not. Surgery is required when it is determined that removal of the tissue is necessary.

Decisions for surgery are based on the following factors: the location and size of the tumor, the number of tumors, the age and overall health of the patient, the likelihood of success and the time since the last surgery. If surgery is chosen to remove the affected tissue from the brain, it is called a resection. A gross total resection is when the entire visible tumor has been removed. A sub-total resection is when all of the tumor is not, or cannot, be removed. All surgical options should be thoroughly discussed with the patient and family including the potential risks and benefits of the proposed procedure.

- **Radiation.** This treatment differs according to the type and location of the tumor. Intensity Modulated Radiation Therapy (IMRT) is a precise way to aim beams of radiation, from many angles, to cover a tumor. The treatment is split into a number of small doses, or fractions of radiation. This protects healthy tissue while attacking the cancerous tissue. This is the most common method of radiation for patients with primary brain tumors.

- **Stereotactic Radiosurgery.** This can be performed with or without head frames, or an outside structural guidance device. It is used most often for benign tumors of the brain, or small metastatic tumors. This gives doctors the ability to achieve a higher level of accuracy in pinpointing the exact location of the tumor. It may be used alone or with other brain cancer treatments such as chemotherapy, surgery or whole brain radiation therapy. If your doctor recommends this treatment, more details will be provided by his office or your treatment team.

- **Chemotherapy.** Some types of brain tumors have been found to be responsive to different types of chemotherapy. Chemotherapy is the treatment of tumors by drugs that have toxic effects on tumor cells as they divide or multiply. There are many types of chemotherapy drugs and most are given orally or intravenously. Some drugs are given alone or are used in combination with other drugs. Other drugs may be administered to counter any side-effects of chemotherapy. A discussion of the drugs that are recommended, along with their risks and benefits should be reviewed with your doctor and others on your treatment team.

- **Alternating Electric Field Therapy (tumor treating fields).** This type of therapy may be recommended to you by your treating physician if you have a glioblastoma tumor that is located in the upper brain and you have a good performance status.

**Your Treatment Team**

Many caring professionals are on hand to help you through the treatment of your brain tumor or cancer. These well-trained professionals also have many years of experience in treating brain tumors or cancers like yours. They can help you understand your treatments and give you advice that will provide you greater control over your treatment. You will also find them willing to answer any questions or address any concerns you or your family may have regarding your treatment, tests, etc. The following professionals will be part of your treatment; however, you are the most important member of the team.
• **Neurologist.** A doctor specializing in the diagnosis and treatment of disorders and diseases of the Central Nervous System (CNS).

• **Neuroradiologist.** An expert in imaging techniques and specializes in the interpretation of diagnostic scans of the brain, spinal cord and nervous system.

• **Neurosurgeon.** Specializes in the diagnosis, treatment and surgical management of disorders and diseases of the CNS.

• **Neuropathologist.** Specializes in the diagnosis of neurological disorders and diseases through the microscopic examination of biopsied tissues (tumor cells).

• **Neuro-Oncologist.** A cancer doctor who specializes in the treatment of cancers and tumors affecting the CNS.

• **Radiation Oncologist.** A doctor specializing in the delivery of radiation therapy.

• **Nurse Practitioner.** A registered nurse with additional education and training who has the authority to perform physical exams, order common diagnostic and laboratory tests and in most cases can prescribe certain medications. Usually abbreviated “APRN” (Advanced Practice Registered Nurse).

• **Physician Assistant (PA).** A certified health care worker who may perform physical exams, identify health problems and plan treatment under the direction of a medical doctor. A PA has skills and responsibilities similar to a Nurse Practitioner.

• **Neuro-Oncology Nurse Specialist.** A registered nurse specializing in patient education and support services for brain tumor patients.

• **Behavioral Oncologist.** A psychiatrist who provides supportive, emotional and psychological care for patients and their families. (This person may work with a team of advanced practice registered nurses to help patients and families cope with the stress of tumor diagnosis.)

• **Neuro Nurse Navigator.** A specialty certified nurse that is trained to manage the patient’s care from the time of diagnosis. (This will be your point-of-contact person throughout your treatment. They can answer most of your questions and make helpful referrals.)

• **Neuropsychologist.** A licensed psychologist who specializes in understanding the brain/behavior relationship. (They are able to diagnose or determine how much, if any, brain damage has occurred after your treatment. If recommended, a visit made prior to surgery or treatment will help this doctor better determine a proper diagnosis.)

• **Medical Social Worker (MSW).** A licensed social worker who assists patients and families with health-related problems and concerns. MSWs help locate appropriate health care, legal resources and/or financial aid.

• **Nutritionist.** A person who understands the dietary needs of the person with the tumor in order to make sure that the patient has the proper nutrition for maximum recovery.

• **Physical Therapist.** A trained specialist who helps restore physical function, improve mobility, relieve pain and prevent or limit any possible permanent physical disabilities.

• **Speech Therapist.** A trained specialist who helps people recovering from brain tumor surgery. They help people restore their ability to eat and swallow; to regain physical speech; and regain any loss of cognitive function such a memory.

• **Occupational Therapist.** This trained professional helps people recovering from brain surgery relearn self-care, grooming and other activities of daily living such as meal preparation and light housekeeping skills.
• **Rehabilitation Counselor.** A specialist who helps people deal with the personal, social and vocational effects of their surgery in order to increase their capacity to live independently.

• **Clinical Psychologist.** A licensed professional who can help patients and their families adjust to the effects of the treatment of tumors or cancer.

• **Physiatrist, or Physical Medicine and Rehabilitation Specialist.** A physician who specializes in physical medicine and rehabilitation. Physiatrists specialize in restoring optimal function to people with injuries to the muscles, bones, tissues and central nervous system.

**Preparing for Your Visit**

The treatment of your brain tumor will require you to visit many doctors and specialists. It is important to be prepared for your visits. Preparing for your visit will save time and make sure that your treatment is properly coordinated and that your questions and concerns are addressed. The following tips will help you to be a better patient and participant in your treatment.

• Be on time for your appointment. You will need to keep a good calendar, and schedule, of who you are to see, when you are to see them and where they are located. This may be a good task to delegate to a family member, or friend who wants to help.

• Always bring a list of current medications including the dosage and the reason for the prescription. Also let the health care provider know of any over-the-counter medications or supplements that you take as there may be unpleasant drug interactions that can be avoided with this knowledge.

• Bring along a diary that lists any problems that you may be having. Try to be as specific as possible. For example, if you are dealing with headaches, a journal would record the number of headaches you have in a day and when they occur. You will also want to give a pain scale so the doctor has a clear idea of your exact problems.

• Write down any questions and concerns you have. Don’t trust your memory as it is too easy to get distracted and forget to ask a question until after the doctor leaves. Try to write down the answers. Again, this is a great job for a close family member or friend.

• Record any instructions that the doctor gives you. Make sure you understand them and that you record the time, date, and place of the next appointment. You will find some useful apps for your cell phone that can help you keep track of appointments and help record doctors’ instructions. Also, there is a worksheet in the back of this book that will give you a great outline to help you prepare for your appointments.

• Be sure to take your medications exactly as prescribed by your doctor or medical professional. However, in the event of any side-effects, call your doctor immediately! There may be a simple remedy for this or another medication may be prescribed. You will want your healthcare provider to know that you can be trusted to follow his or her directions.
**Involving Your Family**

Invite your family to join you in any life-style changes that your doctor recommends. Such recommendations may include smoking cessation, changes in your diet or adding an exercise routine to your day. These changes will not only help you, they will help your family too.

- Delegate much and often. Often people will ask what they can do to help and this is a great time to provide them with something that they can do to assist you. You can ask them to help you keep your schedule and medications organized. They may be willing to handle your communications and keep people updated on your progress through social media. It could also be something as simple as mowing the lawn, running errands, cooking a meal, doing the laundry or watching the children while you have to be out of the house.

- Locate your resources. The BIAK Brain Tumor Program works hard to collect information about many of the resources that you may need. Since many of these resources have long waiting lists, you will want to apply for them as soon as possible. One example of this is Social Security Disability Insurance or SSDI. The application for SSDI is often a long process and it is important to remember that your payments will be based from the time you first applied. Also, you may need help in replacing lost earnings, making co-payments or paying for your medications. This journal and the BIAK Resource Journal will help you locate these resources and how to contact them.

- Arrange for respite. Since it is not uncommon for recovery and rehabilitation to require prolonged care, your caregivers will need to take a break from time to time. This is good for you, too, and allows them time to attend to some personal business. This will help reduce stress on you as well as your caregiver. Friends and other family members may be enlisted to provide some in-home care while the primary caregiver is off to run errands or to help reduce stress. The Kentucky Department for Aging and Independent Living and the Traumatic Brain Injury Trust Fund may provide some limited respite. The Department for Aging and Independent Living has trained respite providers in your area and the TBI Trust Fund can even help pay for some of this respite. Information about these programs is located in the BIAK Resource Journal.

**Understanding Complementary and Alternative Treatments**

Nearly one-third of all cancer patients seek some form of complementary or alternative medicine along with the therapy they receive from their treatment team. These treatments are based upon historical or cultural practices and lack any scientific validation, such as controlled tests. Conventional medication uses the concept of evidence-based best practices in their suggested treatment. That simply means that the treatments of conventional medicine have been proven to work based upon careful study and clinical experience. However, complementary and alternative treatments may be useful in helping to reduce the side effects of medication and stress.
Terms to know about Complementary and Alternative Medicine

- **Complementary Medicine** represents all therapies not considered or used by conventional medicine, but rather works alongside conventional medical treatment. Many of these complementary treatments are now offered to patients at cancer centers. Common examples of complementary medicine are: acupuncture, deep breathing, mindful meditation and massage therapy. These treatments may help you relax, manage pain and cope effectively with the effects of your treatment.

- **Alternative Medicine** is a term that refers to the use of non-mainstream treatments as opposed to conventional medicine. Some examples of alternative medicine are: special diets, teas, herbal supplements or “natural” medicines. Care should be taken to make sure that the chemicals you are putting into (or withholding from) your body will not conflict with the medications your team prescribes. You should discuss any alternative therapies with your doctor and pharmacist before starting.

- **Ancient Healing Systems** are usually practices from China or India that have been used in those countries to promote healing. These treatments often focus on channeling the body’s energy to heal itself.

- **Homeopathy** is the process of using small amounts of certain “natural” chemicals to help stimulate the body’s healing process.

- **Naturopathy** is a process that uses non-invasive methods such as massage therapy, herbal remedies, exercises and lifestyle changes to promote the body’s healing process.

It is important to understand what these complementary and alternative treatments can and cannot do to help you in your treatment. Complementary and Alternative Practices may be able to help you manage pain, ease nausea, relax and maintain mobility and flexibility. Treatments that are positive and result in habits that lead to better physical and emotional health may be used along with your treatment with the knowledge and advice of your healthcare team members.

Neither complementary nor alternative medicines can replace conventional medicine or cure cancer. You may hear claims that a particular treatment is better than conventional medicines or reports of miraculous cures. Exercise caution when you hear these claims! While it is tempting to believe these claims, your team members have seen people harmed by ignoring the advice of the treatment team in hopes of a miraculous cure. Be sure to talk openly with trusted members of your treatment team before trying any of the alternative treatments.
Using Technology to Manage Your Treatment

Advancements in technology make it much easier for you to track your health and manage your care. Smart phones such as an i-Phone or an Android Phone allow access to applications, or apps, that help you to organize your day, track your medications and monitor your health. Many of these apps are free and others are very inexpensive. The following table lists some apps, their features and price, if any.

<table>
<thead>
<tr>
<th>App Name</th>
<th>Website/Price</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living With Cancer, sponsored by Pfizer</td>
<td><a href="http://www.thisislivingwithcancer.com">www.thisislivingwithcancer.com</a> Free to download</td>
<td>This app offers social network support, helps with daily tasks, tracks how you are feeling (mood, sleep, pain, etc.), allows notes from doctor visits, organizes and stores documents in one place.</td>
</tr>
<tr>
<td>Cleveland Clinic</td>
<td><a href="http://www.my.clevelandclinic.org/mobile-apps">www.my.clevelandclinic.org/mobile-apps</a> free</td>
<td>Get the latest health and wellness tips from Cleveland Clinic and stay up to date on cancer information and clinical trials.</td>
</tr>
<tr>
<td>Cancer Terms Offline Dictionary</td>
<td>Free</td>
<td>This app helps you decipher medical jargon and medical terms that are unfamiliar to you. These terms are cancer specific and this app is not useful for other medical terms.</td>
</tr>
<tr>
<td>Chemo Wave</td>
<td>Free</td>
<td>Helps you keep track of chemotherapy appointments, manage medication schedule and record any side effects you may experience. Also allows you to track your mood, sleep, activities and steps.</td>
</tr>
<tr>
<td>My Medical</td>
<td>4.99</td>
<td>This contains a mini database to help store all your medical information.</td>
</tr>
<tr>
<td>Medication List</td>
<td>Free, extended program available for 1.99</td>
<td>This puts everything in one place on your phone. It keeps track of appointments, medication lists, doctors, clinics, surgeries, etc. It also allows you to list any complaints you need to discuss with the doctor and the doctors replies.</td>
</tr>
<tr>
<td>Awesome Note</td>
<td>3.99 or there is a free version with ads</td>
<td>Awesome Note is an app that will help you organize everything from medical information to soccer practices. Though not created solely for medical purposes, it does a fine job of helping you to keep up with the hustle and bustle of life, which we all know doesn't stop when you are diagnosed with cancer. It contains shopping lists, to-do lists, schedulers, memos, email, and just about everything else to help you keep on top of tasks.</td>
</tr>
<tr>
<td>EverNote</td>
<td>Free</td>
<td>This app helps you stay organized, save ideas and improve productivity by enabling you to capture photos, create to-do lists, and recover voice reminders and more. This app can be accessed across all the devices a person may use.</td>
</tr>
<tr>
<td>Touch Calendar</td>
<td>$3.38</td>
<td>Makes viewing your calendars easy. See your whole calendar at a glance. This app is especially useful for people with attention problems who do better with fewer steps.</td>
</tr>
</tbody>
</table>
You may also want to visit a review of the best 10 apps available, written by the Cancer Network, at
www.cancernetwork.com/blog/10-best-oncology-apps; or Cancer Care’s list of best apps at

There are a number of on-line programs that work to improve cognitive skills such as memory. One of these
is Lumosity: Brain Games & Brain Teaching (www.lumosity.com). Ask your healthcare provider for their
advice and recommendations. You may also research the cost of programs like this to make sure you can fit it
into your budget.

For those who do not wish to use this technology, traditional devices such as a written diary, calendar or
organizer also works well. Consider playing crossword puzzles or even some board games, which may help
improve cognitive functioning.

**Making Future Arrangements**

This is a very sensitive area for many people. However, making end-of-life decisions is always a good idea
even when there is no immediate, life-threatening situation. These decisions do not invite the worst to
happen; instead, it is a great stress reducer that answers some delicate questions before the need arises,
avoiding the need of decision making while coping with grief.

Another advantage of making these decisions in advance is that you can be assured that your requests will be
carried out. Furthermore, you are in charge of your treatment and with good communication, your family can
confirm those decisions knowing that they are complying with your wishes. Among the issues you can decide
in advance are:

- Temporary guardianship. This is someone you appoint who will be able to make business and
  medical decisions for you when you are too sick to make them yourself.
- Location of important documents such as deeds, wills and insurance policies.
- Information about other financial accounts and passwords.

One resource available in making these plans is LivingSmart Software. This program allows you to cover
almost every imaginable need you may face. You can learn more about this program at
www.livingsmartsoftware.com. The material available in this software will help you make thorough
preparations.

**Palliative Care and Hospice**

Although palliative care and hospice may be offered by the same provider, they are different programs. The
main difference between palliative and hospice is that hospice care is provided when the patient is no longer
receiving curative treatment for their underlying disease. Palliative care, on the other hand, is given to
patients with serious illnesses such as yours, while still receiving curative treatment.
Palliative care helps you manage the pain and stress of the symptoms you are experiencing. It does this in four ways: pain and symptom control; communication and coordination; emotional support; and family and caregiver support.

Pain and symptom control will help you with the identified symptoms you are struggling with. Examples may include problems breathing, fatigue, depression, insomnia, or bowel and bladder problems. The team will provide treatments in order to offer some relief. Examples of these treatments are medication, massage therapy and/or relaxation techniques.

Your palliative care team will carefully communicate your needs to your doctor and your family. They will assist in making care decisions, coordinating care and setting goals for your treatment.

Palliative care providers are often concerned about the total person and address any social, psychological, emotional or spiritual needs you may have. These trained professionals will work to keep you healthy physically, mentally and emotionally.

Palliative care also helps your family by providing services such as helping with insurance and Social Security concerns. In addition, they may help by answering questions about any benefits that are available.

Most insurance plans cover palliative care and since the palliative care team works with your medical team, there should be no change of doctors. Be sure to ask your doctor or nurse about receiving palliative care.

If your medical providers don’t have ready access to a palliative or hospice team, you can reach the National Hospice and Palliative Care Organization (NHPCO) at 1-800-658-8898. This organization represents palliative and hospice care providers across the nation. To reach them, send an e-mail to caringinfo@nhpco.org or visit their Web site at www.caringinfo.org.

Top 10 Things a Caregiver Should Know


1. **Communicate openly.** Healthy communication between you and your loved one living with cancer can reduce frustrations and help both of you manage difficult emotions, such as fear. Everyone communicates differently, so try using various techniques, including gestures, expressions and touch. Be realistic and flexible in your communication, always taking your cues from your loved one. And convey your openness to all conversations – even the tough ones.

2. **Educate yourself.** Many cancer patients might not understand – or are not ready to digest – the medical information associated with their diagnosis. As a caregiver, you may need to help interpret treatment options and manage physical symptoms, all with no previous medical training. It’s normal to feel unprepared to make informed decisions, but numerous resources exist that can help. Doctors, nurses and pharmacist are all helpful sources of information, so get to know the members of the health care team. Take notes and ask questions during visits until you gain a good understanding. Reputable cancer education Web sites can also help you self-educate.

3. **Get organized.** As a caregiver, you’ll likely be confronted with a lengthy list of practical life issues, such as providing transportation to appointments, talking with the medical team, managing the
home, informing family members and delegating. Paying for expensive medications and monitoring insurance coverage also become important issues. You may want to use the doctor visit preparation form in this book to help you prepare for doctor visits.

4. **Don’t overfunction.** Due to the side effects of some medications and hectic appointment schedules, you’ll need to assume many of the jobs formerly done by the patient. Initially, you may have a tendency to overfunction for your loved one in an attempt to help as much as possible. However, try not to do anything as a caregiver that the patient is capable of doing alone. Evaluate your loved one’s ability and willingness to participate in daily self-care and go from there. Do your best to keep life as normal as possible, and let your loved one decide when help is needed.

5. **Embrace change.** Cancer is not always predictable, so what you hope for as a caregiver may need to change throughout the course of your loved one’s battle. You may have a lofty hope for a return to normalcy one day and a simple hope for less suffering the next – and that’s okay. Just do your best to remain realistic and flexible. Also do your best to embrace the reality that traditions, especially around the holidays, can’t always be carried out. Instead, make new ones to cherish and look for ways to treasure each day just as it is.

6. **Remember your own basic needs.** Many caregivers experience both physical and emotional fatigue, often neglecting their own needs for nutrition, adequate sleep, exercise and socialization. Do not underestimate the toll this can take on your health and well-being. Stick to your normal routine as much as possible, and don’t feel guilty when you take time to care for yourself. Keeping yourself strong is important for the person for whom you are caring.

7. **Plan time for yourself.** Set aside time each day to do something you enjoy. Meet a friend for lunch, take a walk or watch a funny movie. Most importantly, don’t think of these activities as selfish. It’s imperative to occasionally escape from your duties as a caregiver. Research is showing that self-care is medically necessary to keep yourself physically and mentally strong.

8. **Ask for help.** It is not realistic to think you can do it alone. Family and friends often want to help, but they may not know how. To focus their desire, create a clear list of areas where you could use a hand and ask them which tasks they would like to tackle. Continue to reach out until everything is covered. Asking for help can relieve some pressure and leave you with a little time for yourself.

9. **Seek out support.** Many caregivers have to suspend their own lives and report feelings of loneliness and isolation. About one-third say they have some strain or stress on their social and physical well-being, including anxiety, depression, spiritual challenges and sleep problems. Although the caregiver’s depression can be at the same level as the patient’s, many caregivers don’t realize that they need support, too. Don’t overlook the local support groups or educational programs offered by many cancer centers. Many outstanding resources on the Web can also be beneficial. Talking with other caregivers – either in person or online – can help provide the support you need.

10. **Enjoy your role.** While caregiving will likely be the hardest job you ever do, it also may bring you closer to your loved one living with cancer. Caregiving allows you to demonstrate your love and respect, and it can give you a deep sense of satisfaction and accomplishment. Through caregiving, you may find a new sense of purpose in life, and you’ll undoubtedly learn things about yourself that you didn’t know before.
The following resources are available to help brain tumor and cancer survivors cope with the complex needs that arise with a diagnosis of brain tumor. The needs and resources vary as do the various qualifications. For more information about other resources, please consult the BIAK Resource Journal. It is available free for the asking and is accessible on our Web site: www.biak.us.

This section covers an array of services that are relevant to care and treatment of a brain tumor. However, should you have other questions, please feel free to call the Brain Tumor Alliance of Kentucky. We are a division of the Brain Injury Alliance of Kentucky and you can reach us toll free at 1-800-592-1117.

**Medical Care and Health Insurance**

**Federal and State Programs**

**Disability.gov**

Disability.gov is the federal government Web site for comprehensive information on disability programs and services in communities nationwide. The site links to more than 14,000 resources from federal, state and local government agencies; academic institutions; and nonprofit organizations. You can find answers to questions about everything from Social Security benefits to employment to affordable and accessible housing.

New information is added daily across 10 main subject areas – Benefits, Civil Rights, Community Life, Education, Emergency/Preparedness, Employment, Health, Housing, Technology and Transportation.

Web Site: https://www.dol.gov/odep/topics/disability.htm
Call toll free: 1-866-633-7365

**Healthcare.gov**

This is a government run Web site that will help you find out about programs such as the pre-existing healthcare programs in each state.

Web Site: www.healthcare.gov
Call toll free: 1-800-318-2596

**Social Security Administration**

(Please visit the Federal/State Resource section of the BIAK Resource Journal.)
National Council on Aging Benefits Checkup

This service is available to senior citizens and is a valuable resource for governmental programs to help pay for medical and/or household expenses.

Web Site: www.benefitscheckup.org
Phone: (571) 527-3900

State Programs

Benefind

This is not an assistance program, but it is a good way to access information to any public assistance or benefits that a Kentucky resident will need.

Web Site: www.benefind.ky.gov
Toll free: 1-855-306-8959

Other Kentucky Programs

Other programs offered by Kentucky that can offer assistance to Kentucky residents are:

- The Department for Aging and Independent Living
  - Caregiver Support Services
  - State Health Insurance Assistance
  - Personal Care Attendant Program
  - State Health Insurance Assistance
  - Traumatic Brain Injury Trust Fund
    - To contact the TBI Trust Fund, call toll free: 1-855-816-9577
- Department for Medicaid Services: Acquired Brain Injury Medicaid Waiver
  - Toll free: 1-866-878-2626
Cancer Resource Sites

American Brain Tumor Association

This organization has information that covers a wide array of needs such as:

- Research for a cure
- Assistance finding financial resources
- Help with equipment expense
- Grants and scholarships for camps
- Insurance premium expenses
- Prescription assistance
- Resources for local social services
- Transportation, travel and lodging for treatment

Web Site: [www.abta.org](http://www.abta.org)
Toll Free: Careline 1-800-886-2282

American Cancer Society

This agency has a listing of all possible social service organizations in your area on their Web site.

Web Site: [www.cancer.org](http://www.cancer.org)
Toll Free: 1-800-227-2345

National Brain Tumor Society

This organization helps with information regarding financial and insurance resources.

Web Site: [www.braintumor.org](http://www.braintumor.org)
Toll Free: 1-617-924-9997

Optune

Information on glioblastoma and tumor treating fields.

Web Site: [www.optune.com](http://www.optune.com)
Non-Governmental Assistance

Financial Assistance

This section covers an array of financial services such as insurance co-pays, medication and a host of other expenses that arise during treatment of a brain tumor. Please check for requirements and availability of funds.

Cancer Care

Cancer Care offers resources for cancer related questions and many publications. Cancer Care offers varying financial assistance for transportation, child care, and medications. Go to http://www.cancercare.org to see if you might qualify for any financial assistance.

Web Site: http://www.cancercare.org/
Toll-free: 1-800-813-HOPE (4673)

Cancer Care Co-Payment Assistance Program

Cancer Care’s foundation offers assistance to help cover co-payments for cancer therapy and drugs. Different assistance is offered as funds become available. Go to portal.cancercarecopay.org to see if your cancer diagnoses currently has an open program.

Web Site: portal.cancercarecopay.org
Toll-free: 1-866-552-6729

Clayton Dabney Foundation for Kids with Cancer

Financial assistance to needy families with children who have terminal cancer.

Web Site: www.claytondabney.org
Phone: (214) 361-2600

Good Days

Assists with co-payment, diagnostic testing costs and travel assistance for those under poverty level. Different assistance is offered as funds become available. Go to Web site to see what diseases are currently covered.

Web Site: www.mygooddays.org
Toll Free: 1-877-968-7233
**Mission4Maureen**

Provides financial assistance for: medical bills, child care, house payments, utility payments, transportation and medication.

Phone: (440) 840-6497

**National Children’s Cancer Society**

Financial assistance for families.

Web Site: [https://www.thenccs.org/](https://www.thenccs.org/)
Phone: 1-800-532-6459; (314) 241-1600

**The Sam Fund for Young Adult Cancer Survivors**

Offers financial assistance and on-line support for cancer survivors only.

Web Site: [www.thesamfund.org](http://www.thesamfund.org)
Phone: (617) 938-3484

**United Healthcare Children’s Foundation**

Financial assistance for children (ages 16 and younger) who are not fully covered under their parent’s insurance.

Web Site: [www.uhccf.org](http://www.uhccf.org)
Toll Free: 1-855-698-4223
Prescription Assistance

GlaxoSmithKline (GSK) Drug Assistance Program

Prescription assistance for GlaxoSmithKline drugs.

Web Site: [www.gskforyou.com](http://www.gskforyou.com)
Toll Free: 1-888-825-5249

Partnership for Prescription Assistance

Information about prescription assistance programs near you.

Web Site: [www.pparx.org](http://www.pparx.org)

RxAssist

A directory of prescription assistance programs.

Web Site: [www.rxassist.org](http://www.rxassist.org)

RxHope

Web Site: [www.rxhope.com](http://www.rxhope.com)

Rx Outreach

Mail order pharmacy for those who apply.

Web Site: [www.rxoutreach.org](http://www.rxoutreach.org)
Toll Free: 1-888-796-1234
Travel and Lodging

In some instances, you may be sent to a distant facility for treatment and you and/or your family may need assistance with the travel and lodging expenses. The following sites will help with these needs.

**Angel Flight for Cancer Patients**

Transportation for treatment. Helps people find free or reduced commercial flights for cancer patients.

Web Site: [www.angelairlinesforcancerpatients.org](http://www.angelairlinesforcancerpatients.org)
Toll Free: 1-800-296-1217

**Lifeline Pilots**

Transportation for treatment.

Web Site: [lifelinepilots.org](http://lifelinepilots.org)
Toll Free: 1-800-822-7972

**Hope Lodge**

Sponsored by the American Cancer Society, Hope Lodge provides housing without you having to worry about the cost. These facilities are in various locations, so please check. The nearest Hope Lodge in Kentucky is in Lexington, Kentucky.

Web Site: [www.cancer.org/hopelodge](http://www.cancer.org/hopelodge)
Toll Free: 1-800-227-2345

**Joe’s House**

Provides a lodging directory for cancer patients needing medical treatment away from home.

Web Site: [www.joeshouse.org](http://www.joeshouse.org)
Toll Free: 1-877-563-7468
Counseling Services

Brain tumor/cancer affects the entire family. Having a brain tumor can be overwhelming, and you may want some additional help dealing with the emotional and practical issues that result from your diagnosis and treatment. A good therapist will be able to help you and your family sort out the changes and feelings that you are facing. The Kentucky Psychological Association is a great place to begin your search.

Kentucky Psychological Association

120 Sears Ave., Suite 214
Louisville, KY 40207
Web Site: www.kpa.org
Louisville Phone: (502) 894-0777

University of Louisville Psychological Services Center

This agency provides affordable services for people in the Louisville metropolitan area. Fees at the Psychological Services Center are determined on a sliding scale, based on your annual household income. Evening hours are also available on Wednesdays.

Web Site: www.louisville.edu/org/psc/
Phone: (502) 852-6782

How to Choose a Therapist

There are many different types of therapy providers: psychologists, licensed marriage and family therapists, and licensed clinical social workers. Below are some tips to help you find a therapist for you and your situation.

1. The Kentucky Psychological Association ensures that their members have the education and training needed to provide effective therapy. They make sure that each therapist receives continuing education and closely monitors complaints against the therapists. The Kentucky Psychological Association can provide you with that information.

2. Ask about their fees and if the therapist accepts your insurance.

3. Do they specialize in treatment of brain tumor or cancer?

4. Does the therapist have any complaints lodged against them? The Kentucky Psychological Association will have that information, too.

5. You may ask others for their experience. Support groups, members of your faith community or your physician may make a recommendation.
6. Ask if you can speak with the therapist for a few minutes to get an idea of their general style. Often, therapists will speak with you briefly free of charge. Think about what you want in a therapist and how comfortable you feel relating to him/her. Having a good rapport with your therapist may be the most critical element of your treatment.

Support Groups

Many people have found the information, encouragement and opportunity to speak to others in similar situations helpful in the process of coping with cancer. The following is a listing of support groups for survivors and families of persons with brain tumors or cancer.

Support Groups in Kentucky

Michael Quinlan Brain Tumor Support Group

Founded in memory of Michael Quinlan, this support group meets monthly at Gilda’s Club, located at 633 Baxter Avenue, Louisville, KY 40204. To learn more about this meeting, please call BIAK at (502) 493-0609 or toll free at 1-800-592-1117.

Web Site: www.biak.us
Phone: (502) 493-0609
Toll-free: 1-800-592-1117

Cancer Support Community of Northern Kentucky

This group has weekly support meetings and has locations both in northern Kentucky and in Cincinnati. You may call the Kentucky number for information about times and locations of cancer support groups in this area.

Web Site: www.mycancersupportcommunity.org
Phone: (859) 331-5568

National Cancer Support Community
(8:00 am – 8:00 pm, general information only, not a crisis line): 1-888-793-9355
Web Sites:

**Brain Tumor Information:**

American Brain Tumor Association.................................................................www.abta.org

Information on Clinical Trials........................................................................www.clinicaltrials.gov

Mayo Clinic..................................................................................................www.mayoclinic.com

National Brain Tumor Society ......................................................................www.braintumor.org

National Cancer Institute .............................................................................www.cancer.gov

**Assistance Information:**

Social Security Administration ......................................................................www.ssa.gov

Kentucky Dept. of Aging and Independent Living ...... https://chfs.ky.gov/agencies/dail/Pages/default.aspx

Department for Community Based Services..............https://chfs.ky.gov/agencies/dcbs/Pages/default.aspx

Family Caregiver Alliance ...........................................................................www.caregiver.org

Brain Tumor Alliance of Kentucky.................................................................www.biak.us
DOCTOR APPOINTMENT WORKSHEET

Provider’s Name: ________________________________

Today’s Date: ________________________________

Previous Appointment __________  Next Appointment __________

Routine _______  Emergency _______  Follow-up _______

QUESTIONS:

1) ____________________________________________

2) ____________________________________________

3) ____________________________________________

Answers

1) ____________________________________________

2) ____________________________________________

3) ____________________________________________

CURRENT MEDICATIONS:

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Listed below are some important telephone numbers. Please feel free to add other important numbers to this sheet for future reference.

- Emergencies (fire, police, EMT) ................................................................. 911
- Suicide Hotline .................................................................................. 1-800-784-2433
- Abuse Hotline .................................................................................. 1-800-752-6200
- Domestic Violence Hotline ............................................................... 1-800-799-7233
- Sexual Assault Crisis Hotline ........................................................... 1-800-656-4673
- Atty. General Welfare/Medicaid Fraud, Neglect and Abuse Line ......... 1-877-228-7384
- Consumer Information and Complaint ............................................ 1-888-432-9257
- Identify Theft Victim Hotline ............................................................. 1-800-804-7556
- IRS Scam Hotline ........................................................................... 1-800-366-4484
- Kentucky Department of Criminal Investigation ................................ 1-866-524-3672
- KY Inspector General Recipient Medicaid Fraud Hotline ................. 1-800-372-2970
- Kentucky Office of Insurance ............................................................. 1-800-595-6053
- KY Ombudsman ................................................................................ 1-800-372-2973
- Medicare Fraud Hotline .................................................................. 1-800-447-8477
- Poison Emergency and Information .................................................. 1-800-222-1222
- Public Service Commission ............................................................... 1-800-772-4636
- Telemarketing No Call List ............................................................... 1-888-382-1222
- Victims Advocacy ............................................................................ 1-800-372-2551
- Brain Injury Alliance of Kentucky ..................................................... 1-800-592-1117

### Phone Numbers that are Important to You

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Note: You may want to have the telephone number of your local Area Agency on Aging, Community Mental Health Center and case manager for ready reference.