

Factors Influencing Quality of Life for Brain Tumor Survivors

A Practical Tool for Navigating Survivorship



Scott Norris
Brain Tumor Survivor
2011

Opening Thoughts

*What we've got here is (a) failure to communicate. - Paul Newman, from the 1967 film
Cool Hand Luke*

As you read the following two quotes, think about the health care system that we are all (hopefully) a part of and how that system is becoming increasingly difficult to navigate. Think also about how the health care system is a service industry, and not just an average service industry, but probably the most crucial set of services we will ever purchase. When we enter the system (*as customers*) we are mortgaging our bodies and our health to people and institutions that we barely know. And failure, whether it be failure of communication, of organization, or of execution, is simply not an option. I thought the oath was, “do no harm.” Well, people, there's a whole lot of harm being done out there.

We think we know what failure looks like. Products don't get purchased. Reorganizations make things worse. Shipments aren't delivered. Things explode. These are the emergencies and disasters that we have nightmares about. Given our strong cultural bias against failure, this probably won't win me any fans, but I think we have no choice but to aggressively redefine the concept to include far more outcomes than our current definition does. Every day, thousands of people call your business' customer support line because they don't understand how to use one of your products. This is a failure. It's a failure worse than if they hadn't bought your product at all. If you care about your company, your customers, and the meaning of value, you'll care enough to reexamine your definition of failure. - Seth Godin, Harvard Business Review

More and more, the quality of care we receive depends on how well we are able to navigate bureaucracies, champion our own best interests, and find the extra support and information we need. - Jason McNichol, PhD, Health Advocacy Solutions, www.HASolutions.org

Introduction

The following quote is from the Institute of Medicine's 2007 report brief, "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs." Although it speaks generally about the needs of cancer patients and their caregivers, it also applies specifically to brain tumor survivors (malignancy or not) and their caregivers.

The failure to address the very real psychosocial health needs of patients and their caregivers is a failure to effectively treat that patient's cancer, plain and simple.

The report goes on to say (and I believe this also applies to brain tumor survivors), "After all, cancer treatment is intended both to extend life and to improve the patients' quality of life. The health care system should explicitly recognize these needs and find ways to meet them. Patients and caregivers deserve no less. ... [W]e need our health care professionals to do a better job recognizing a patient's needs and connecting them to the right services - each and every time, for each and every patient. ... As a person diagnosed with cancer, you should expect to have: satisfying communication with doctors, nurses, and others treating your cancer; doctors, nurses, and others treating your cancer ask you about your needs for information and emotional support; and a health care person or team who works with you to develop and carry out a plan that: links you to the information and support that you need; coordinates your medical, emotional, and social care; and helps you to manage your illness, treatments, and health. ... It's about healing the human being."

A study by the National Brain Tumor Society, "A Needs Assessment of Brain Tumor Patients, Survivors and Loved Ones," parallels the Institute of Medicine report brief when it states: "Many of our findings highlight the need to re-examine what it means to live with a brain tumor diagnosis. The concept of brain tumor survivorship is expanding to include not only quantity of life but also quality of life for people with a brain tumor. Our findings call attention to possible shortcomings in the range of services that are considered to be the standard of care for brain tumor patients and survivors. There is a need for more routine assessments and

services that go beyond standard treatment regimes and holistically address the spectrum of cognitive, physical and psychosocial needs of brain tumor survivors. Special attention to the needs of both patients and their loved ones is crucial to supporting families throughout the brain tumor journey.”

Goals of this Paper

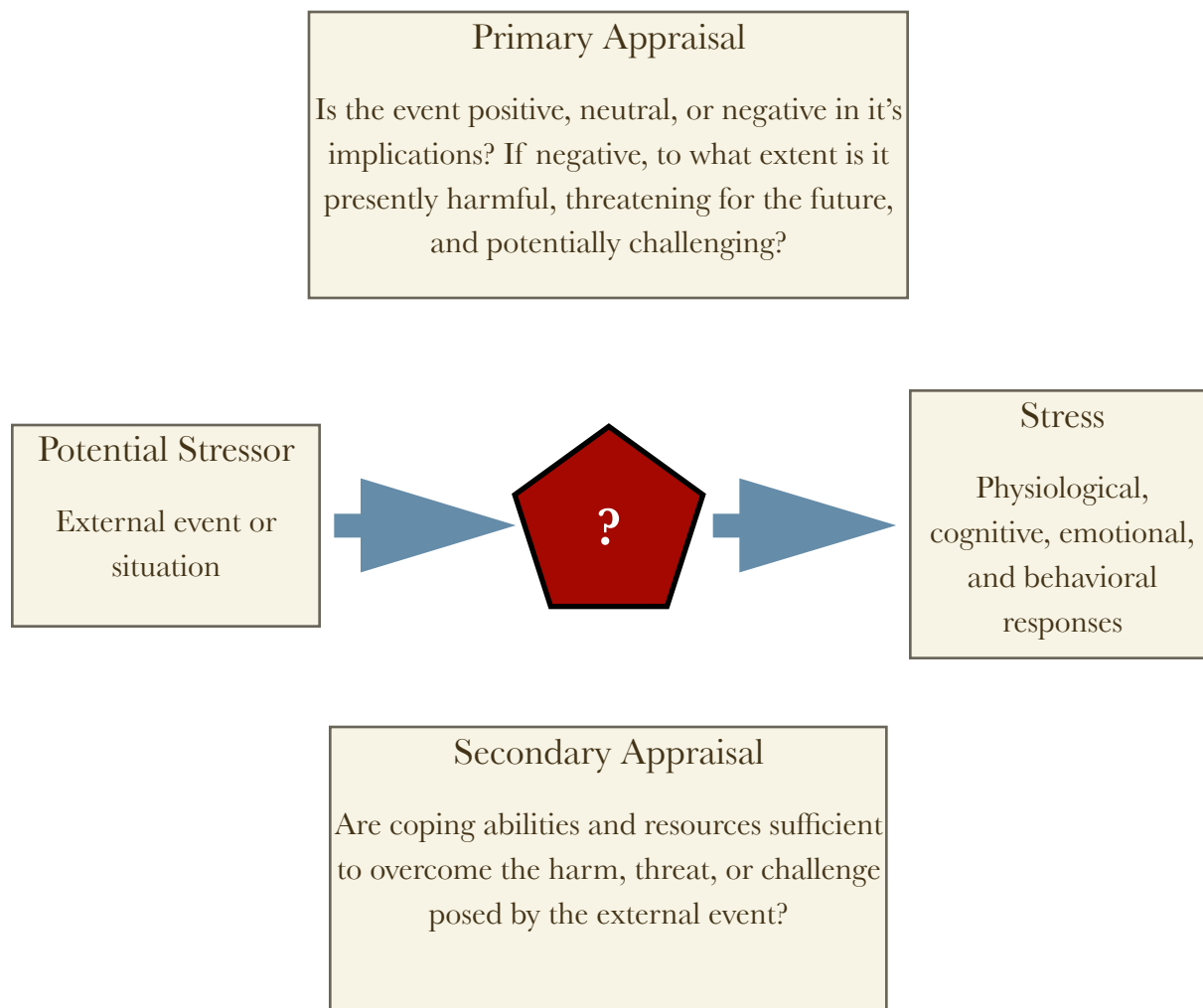
1. I hope to outline various factors that affect the quality of life for brain tumor survivors (based on my own experience and discussions I have had with other survivors, and supported by both the Institute of Medicine’s report brief and the National Brain Tumor Society’s needs assessment cited in the introduction).
2. More importantly, I hope this paper can extend beyond mere description and be a practical tool for brain tumor survivors in helping them identify exactly what they need to navigate the often frustrating day-to-day life of dealing with a brain tumor by providing terms and concepts that they may be feeling but do not quite know how to express.
3. Most importantly, I hope this paper will be a tool that will help improve the quality of life for brain tumor survivors.

If this paper is successful, brain tumor survivors and those who care for them (and for that matter, *all cancer patients and their caregivers*) will be able to take it to their health care team, point to or circle an item on one of the diagrams and say, for example, “I need help with THIS,” or, “I need one of THESE.”

Then it’s up to the medical team to work *across specialties and institutions* to fulfill the needs of the patient. Time and effort will be needed to do this work, but as the Institute of Medicine’s report brief states, “Patients and caregivers deserve no less.”

Stress in Brain Tumor Survivors

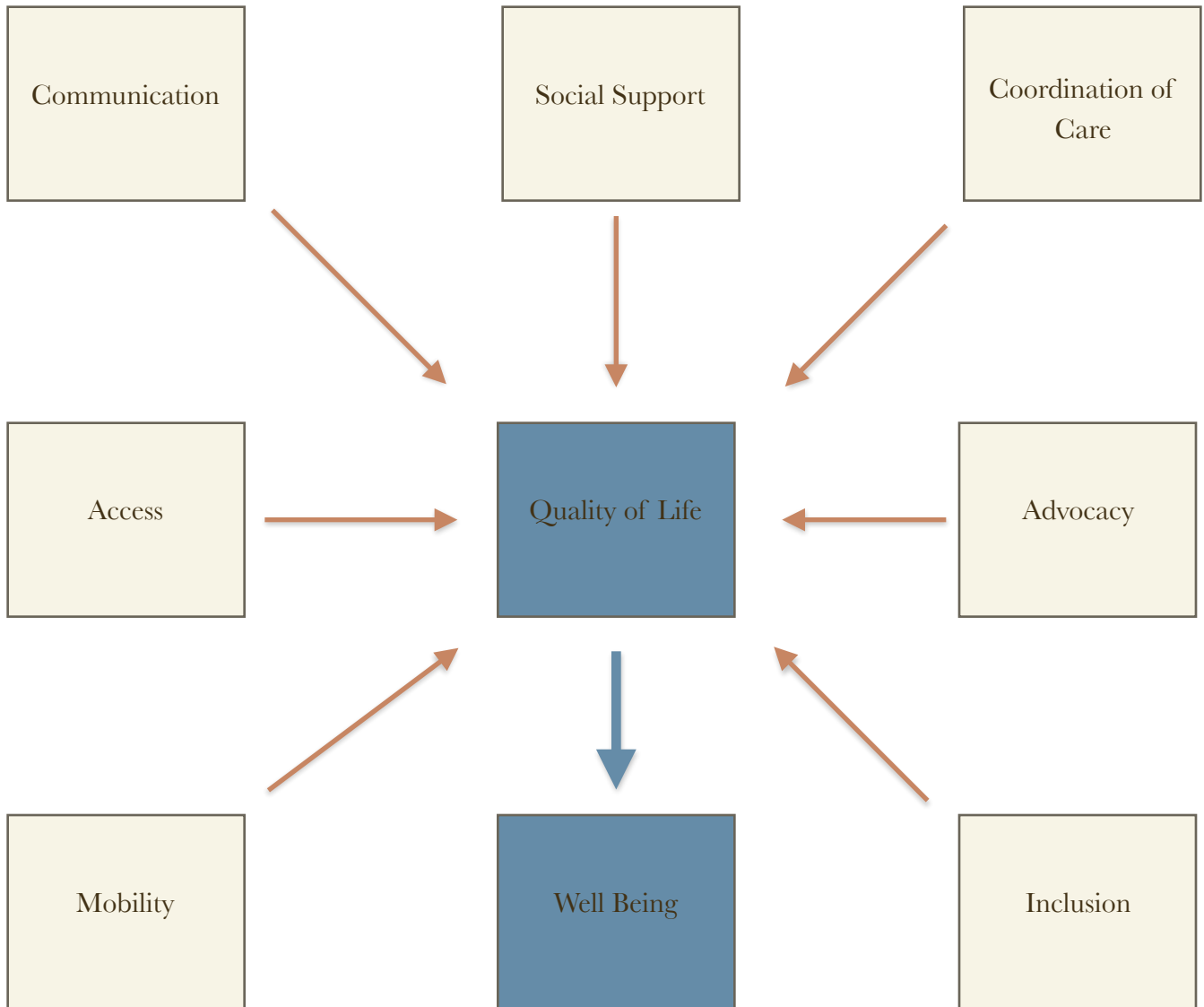
The following is a model of stress adapted from the textbook “Health Psychology,” (5th Edition, 2003) by Shelley E. Taylor.



Brain tumor survivors often find themselves in the red area in the above model, not knowing whether they have the abilities and resources (physical, cognitive, or otherwise) to sufficiently overcome a situation or external event. This can cause much hesitation and stress.

There are various factors, or groups of situations, that can cause such stress. The following diagram outlines these factors and indicates that the ability to navigate successfully through such situations (by possessing or being provided with adequate skills and resources) directly affects not only the quality of life for brain tumor survivors but also lends directly to their overall sense of well being. It is interesting to note that some of these factors even have things in common with the Patient's Bill of Rights.

After the diagram, you will find a description of each specific factor (Communication, Social Support, etc.) along with its corresponding diagram. If you are having trouble in a certain factor, simply take the diagram for that factor to a member of your health care team and point to or circle the area (or areas) of concern that are troubling you, and they should help you.



Communication

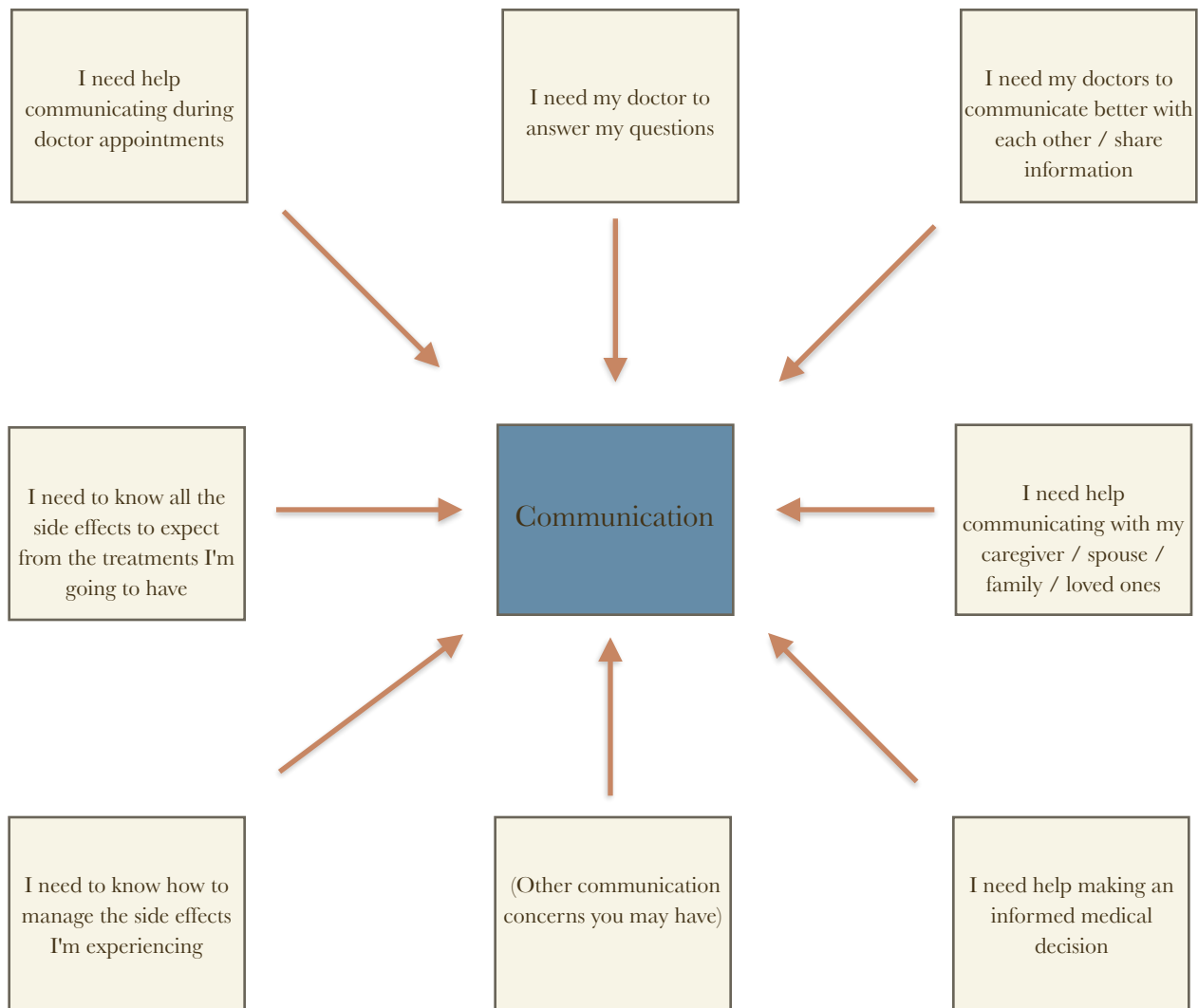
I remember a high school history class in which the teacher was trying to reveal the importance of a common written history, as written in the history book, as opposed to oral history. He whispered a sentence into the ear of one of the students and told him to whisper it to the student behind him, and so on and so on, until the sentence had wound it's way through the classroom. The last student was asked what was whispered into her ear and what she said resembled nothing of the original sentence.

Communication can be troublesome for brain tumor survivors. Since they often have complex medical histories crossing many specialties much communication is required not only between and among the doctors directly involved in treating the brain tumor, but also other specialists who may treat the survivor for other medical issues. If such communication does not exist, it falls on the survivor, as in the example above, to be the oral historian of their own medical history. This situation places a tremendous burden on the patient (who may have cognitive deficits) to find relevant information, translate it, and communicate it to the appropriate doctors. What ends up happening is that many important details of their history are either skewed, repeated over and over again, or forgotten altogether.

This can happen for many reasons. They simply could become confused in an appointment and say the wrong symptom they are experiencing. They could be asked by a doctor to relay a question to another doctor (which is *not* the job of the patient), and forget. They are never told about possible side effects of a treatment, and when they experience symptoms they get different opinions from different doctors as to what is causing them (or worse, they get a flat out *denial* that there is anything wrong). There could be a refusal by one doctor to follow up with another doctor (sometimes even in the *same* office or department) forcing the patient to recall important information that should have been conveyed directly between the doctors themselves (again, *not* the job of the patient - there seems to be a theme emerging here). One or more doctors do not receive a copy of a report. Etcetera. Etcetera. Etcetera. I am confident that every brain tumor survivor can think of examples such as these from their own experience.

Problems also arise when survivors try to communicate with family and friends. Since cognitive deficits, fatigue, and some treatment side effects are often not visible, it is easy for family and friends to fail to comprehend the magnitude of the limitations posed upon the life of the survivor. As a result, survivors often find themselves explaining and justifying to the point where they themselves begin to question their own abilities and resources. This is not supportive, healthy, or productive.

The diagram on the following page shows various situations in which survivors may encounter trouble with communication. If you are having trouble communicating in a certain area, simply take this diagram to a member of your health care team and point to or circle the area (or areas) that are troubling you, and they should help you.



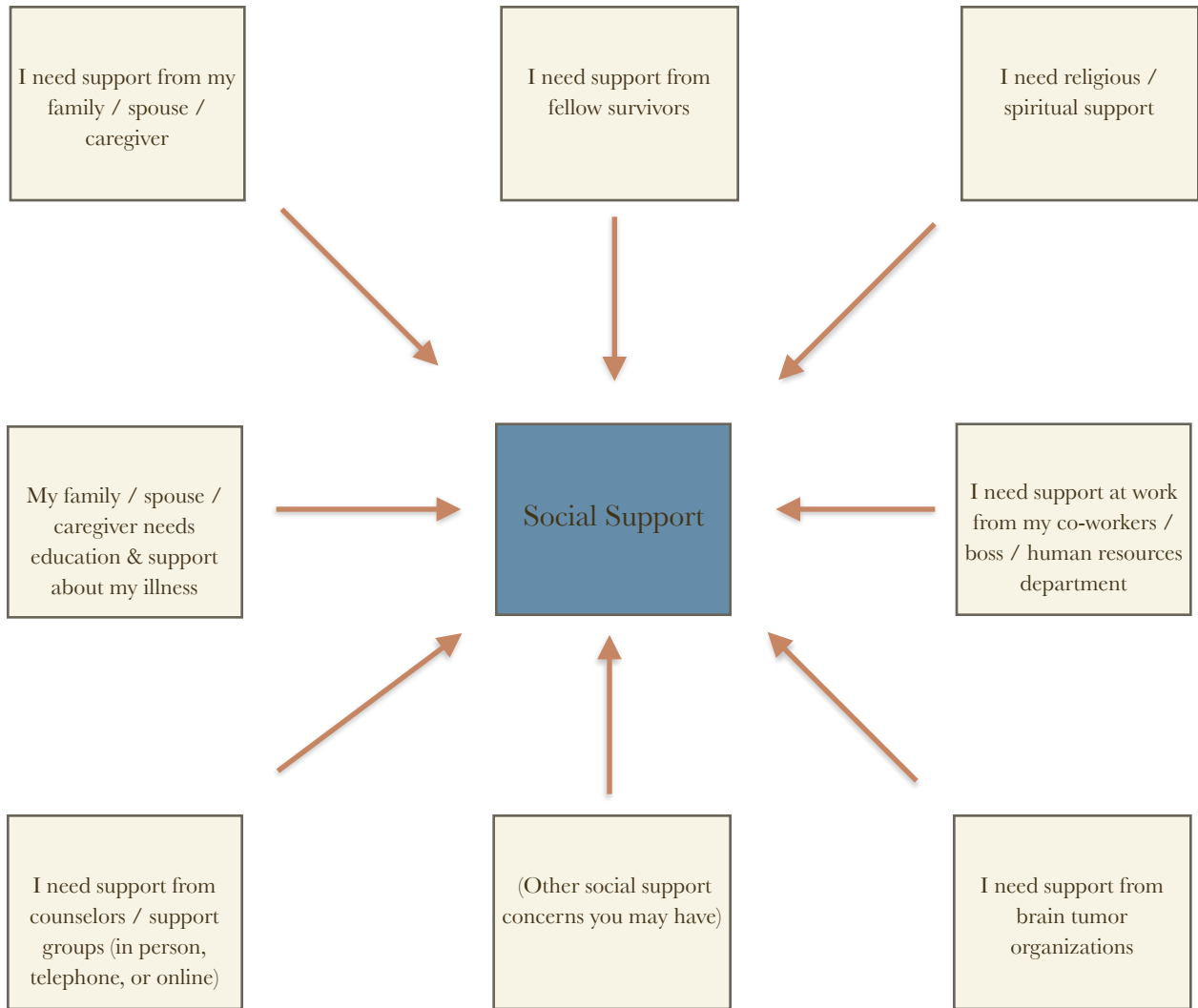
Social Support

Social support can come from many different sources (spouse, family members, friends, fellow survivors, support organizations, employers, counselors, support groups, etc.) and is the safety net for brain tumor survivors.

In much the same way that trapeze artists rely on netting below to catch them should they fall, brain tumor survivors need to know they have a similarly supportive structure of people and organizations on which they can rely. If the safety net is firmly in place, survivors can step out into unknown situations confident that if they stumble, slip, or fall they will be supported.

If, however, the safety net is absent, constantly shifting positions, or made up of a patchwork of loosely connected elements, the survivor can be fearful of even the slightest step forward. Some examples of a weak support system include physicians, medical teams, or health care institutions who have been supportive in the past but then cease to be; family members who move out of state; family members who refuse to respect the boundaries of the survivor and caregiver; family disagreements about what is best for the survivor; friends who no longer call or come by for a visit; bosses, co-workers, or human resources departments who do not understand or accommodate the limitations of the survivor; brain tumor or other support organizations that are restructured or reorganized; people (whether they be doctors, friends, or family) who assume that since you are done with treatment you are somehow magically all better and no longer need support. Etcetera. Etcetera. Etcetera. I am confident that every brain tumor survivor can think of examples such as these from their own experience.

The diagram on the following page shows various situations in which survivors may have needs in relation to social support. If you need support in a certain area, simply take this diagram to a member of your health care team and point to or circle the area (or areas) that are troubling you, and they should help you.



Coordination of Care

A study released in 2011 ("What a Difference a Day Makes," by the California Discharge Planning Collaborative) estimates that one-in-five, or 20 percent of Medicare patients in California end up back in the hospital within 30 days of being discharged for some reason related to the same condition.

According to the author of the study, "Right now when you go to the hospital it's the do-it-yourself model. It's up to you to figure out what to do."

That's right, he said, *"It's up to you to figure out what to do."*

A newspaper article about the study says, "Patients who are released from the hospital too early or without proper planning instructions often wind up back in the hospital after a few days, a problem that's costly to taxpayers and distressing to patients."

The article goes on to say, "Patients, especially those who are elderly and lack social support, are often readmitted because they don't understand their discharge instructions, fail to take their medications or have complications they can't handle."

Now imagine if such patients (or *all* patients) had a care coordinator guiding them, similar in function to the Cancer Care Coordinators offered at the Virginia G. Piper Cancer Center in Scottsdale, Arizona. This type of care coordinator, "serves as a link between the patient, physicians and the treatment facilities and ensures that appropriate education, support and resources are provided to the patient and caregivers. This includes consulting with the patient and family members to describe the comprehensive spectrum of services available; assessing the individual needs of the patient and their family, and providing the necessary education, information, and resource materials; conducting follow-up to ease stress and provide ongoing support and education; and providing education on navigating the healthcare system and strategies for being your own healthcare advocate."

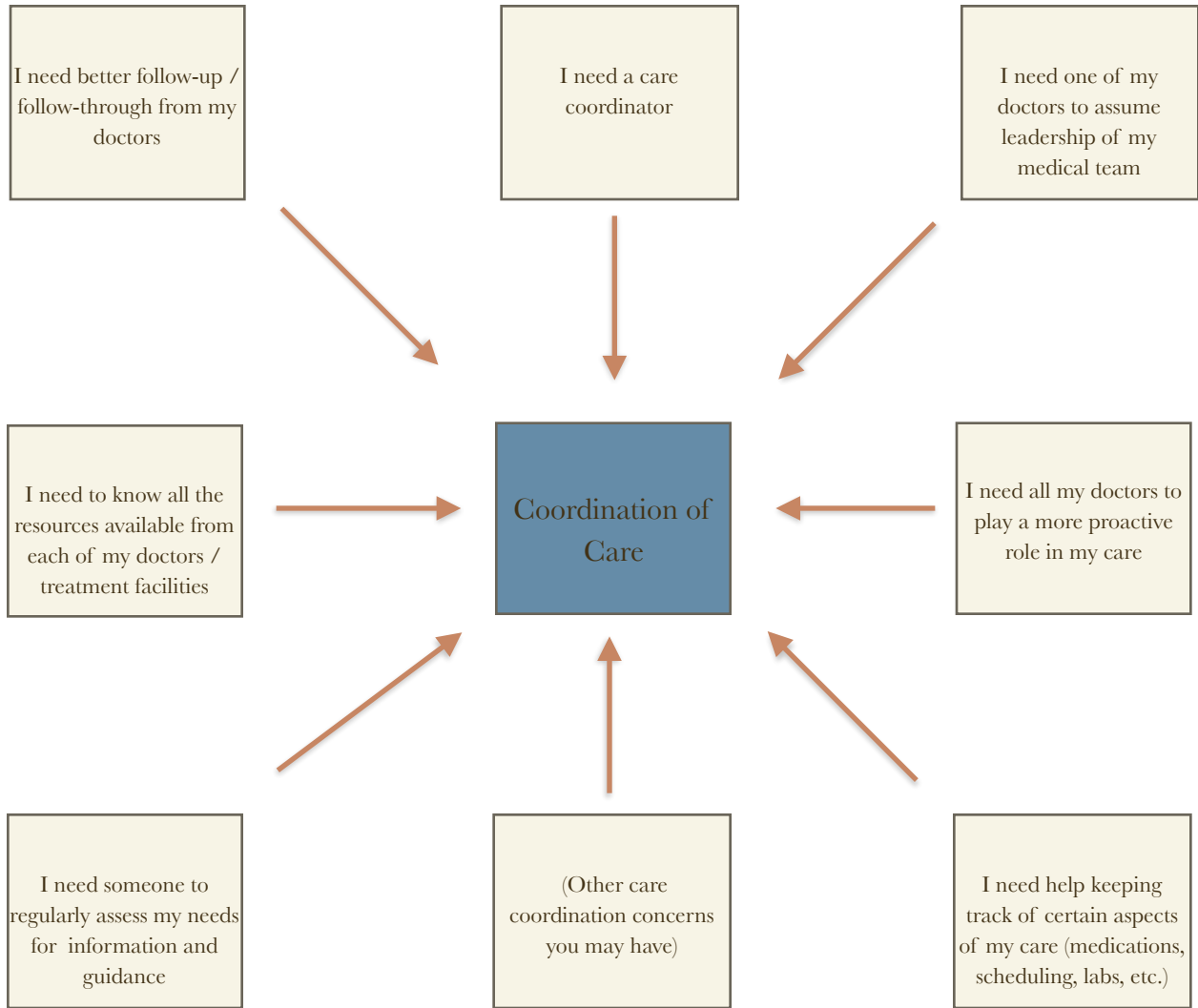
Brain tumor survivors are often under the care of many doctors from a wide range of specialties, and seldom does one doctor assume a leadership role. It's precisely because of this void in leadership that brain tumor survivors and their caregivers

often feel "it's the do-it-yourself model," that it's up to them to "figure out what to do." And it's precisely because of this void in leadership that brain tumor survivors and their caregivers could greatly benefit from some type (*any type*) of care coordination.

It's as if when one doctor is done assessing a survivor through the lens of their own specialty the expectation is that the others will be proactive enough to "figure out what to do" next. What is being overlooked, however, is that "*the others,*" more often than not, are *not* the other doctors, but are the survivors and caregivers themselves who have to do all the figuring out.

I am confident that every brain tumor survivor and caregiver have found themselves in this frustrating situation more than once.

The diagram on the following page shows various needs that survivors may have in relation to care coordination. If you are having trouble in a certain area, simply take this diagram to a member of your health care team and point to or circle the area (or areas) that are troubling you, and they should help you.



Access

My computer has a variety of built-in tools and technologies, grouped under the category "accessibility," all of which are aimed at helping people with disabilities. These tools give the blind and visually impaired, those with speech impairments, and those with cognitive and learning disabilities the ability to access (and to enjoy using) computer technology.

While computer technology has made many advances in the realm of accessibility, there remain many resources, services, and sources of information that are difficult to access for people with special needs, especially brain tumor survivors.

Due to cognitive, physical, and stamina issues so-called "simple" things like accessing routine health maintenance (dental care, eye exams, etc.) can be troublesome for survivors (and are often put off because of other "more important" appointments).

And often survivors do not know when or where to turn for access to rehabilitation services such as physical or occupational therapy, or cognitive (neuro-psychological) testing.

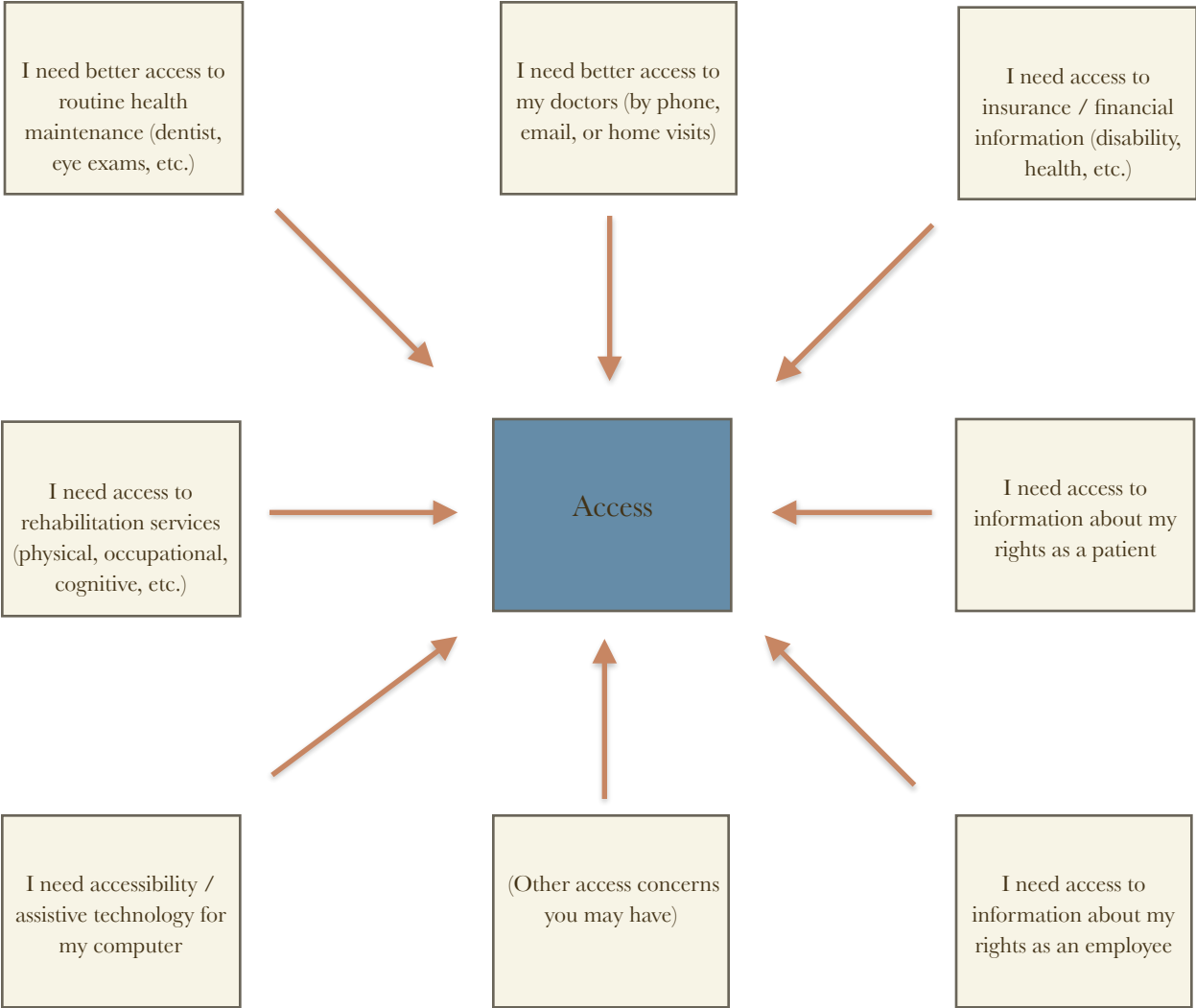
Even accessing doctors in the traditional manner (setting up an appointment, getting to the office, waiting in the waiting room, seeing the doctor, and traveling back home) can be daunting for survivors. Sometimes alternative methods of access (phone, email, or even home visits) are necessary for survivors to get the ongoing care they need and deserve.

There is also critical information that needs to be accessible so survivors can make important decisions. For example, information about what is available to them in terms of disability and health insurance, as well as what their rights are as a patient and an employee.

I am confident that every brain tumor survivor has encountered difficulty with one accessibility issue or another.

The next diagram shows various needs that survivors may have in terms of access. If you are having trouble in a certain area, simply take this diagram to a member

of your health care team and point to or circle the area (or areas) that are troubling you, and they should help you.



Advocacy

Advocacy can be thought of in a general sense as speaking or acting on behalf of another person, or supporting a certain cause.

Various people can advocate on behalf of a brain tumor survivor. Survivors can even advocate for themselves. For example, MRI's can be anxiety provoking, so I sometimes call ahead to see if by chance my favorite technician is working on the day of my scan. That's a simple example of self-advocacy and shows that survivors themselves can attempt to positively influence their own experience.

Much of the advocacy is shouldered, however, by the primary caregiver, whether it be the spouse, family, or other loved ones. Just a few examples of what they do are dealing with insurance companies, setting up appointments, ordering medications, following up with doctors, driving to and attending appointments, and filling out forms. Etcetera. Etcetera. Etcetera. This short list by no means does justice to the countless ways caregivers advocate for survivors.

One of the more comprehensive entities that can advocate for survivors is the private professional healthcare advocate. The following is an excerpt from a paper by PinnacleCare Private Health Advisory which describes the role of the professional healthcare advocate.

The United States offers arguably the best healthcare in the world. Paradoxically, many times that does not result in finding and receiving the best care. ...

All of the professionals in our healthcare system struggle under the crushing weight of cost control measures imposed by insurers and medical institutions, which force doctors to minimize the time they spend assessing, treating, and discussing options with patients and their families. ...

Due to cost constraints and resource limitations, doctors are not able to spend adequate time with their patients and do not necessarily have access to information on all available forms of treatment. In addition, when patients see more than one doctor, their care, medical records, and medications are rarely effectively coordinated. The burden of managing treatment most often falls on the shoulders of the patient and family who are already overwhelmed by having to deal with a serious illness.

Fifty years ago, doctors traveled to the homes of their patients, watched as families grew and spent time talking to their patients. Now the average office visit is 11 minutes and physicians may be seeing as many as 40 patients a day. ...

But there's an exciting new development within the field — the private professional healthcare advocate who is not tied to a single medical institution or network of doctors. ... They manage the entire healthcare process, from collecting medical records from all of the healthcare practitioners a family has seen, to expediting appointments and completing the necessary paperwork, to accompanying patients to appointments to act as an objective "second pair of ears." ...

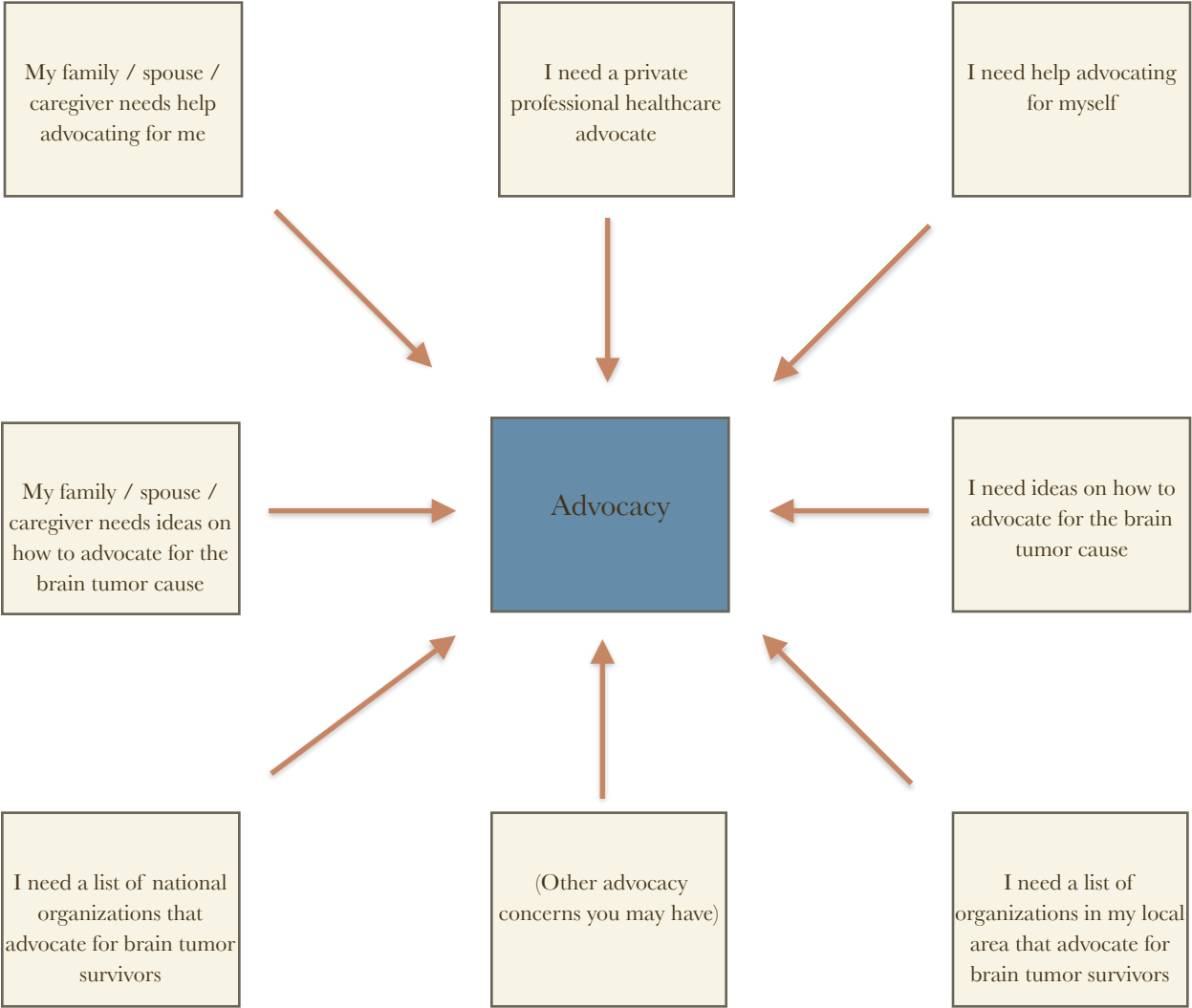
When you're dealing with a serious medical situation, it's only natural to be overwhelmed. People tend to be confused about their options and too distracted or upset to ask the important questions that need to be asked. A professional advocate takes up that role, taking notes, doing research, providing information in layman's terms, and asking questions. This allows the family members to turn their energies toward loving and supporting the patient.

The private professional healthcare advocate may sound similar in some ways to the care coordinator described in the "Coordination of Care" section; however, professional advocates are not tied to a single health care institution as care coordinators tend to be. Plus, professional advocates will most likely charge a fee.

In terms of advocating for the brain tumor cause, there are numerous ways to participate, ranging from simply making a donation to organizing community fundraisers.

I am certain that every brain tumor survivor and caregiver has needed help advocating for themselves, a family member, or a loved one on at least one occasion.

The diagram on the following page shows various needs that survivors and their caregivers may have in terms of advocacy. If you are having trouble in a certain area, simply take this diagram to a member of your health care team and point to or circle the area (or areas) that are troubling you, and they should help you.



Mobility

Mobility and transportation concerns are common among brain tumor survivors.

Whether it be "simply" getting around the home, getting to and from a local appointment, or traveling by plane to a distant health care facility, many obstacles have to be overcome.

For example, some survivors require a cane or wheelchair, a grab bar in the shower, or other assistive technology to ensure safe mobility.

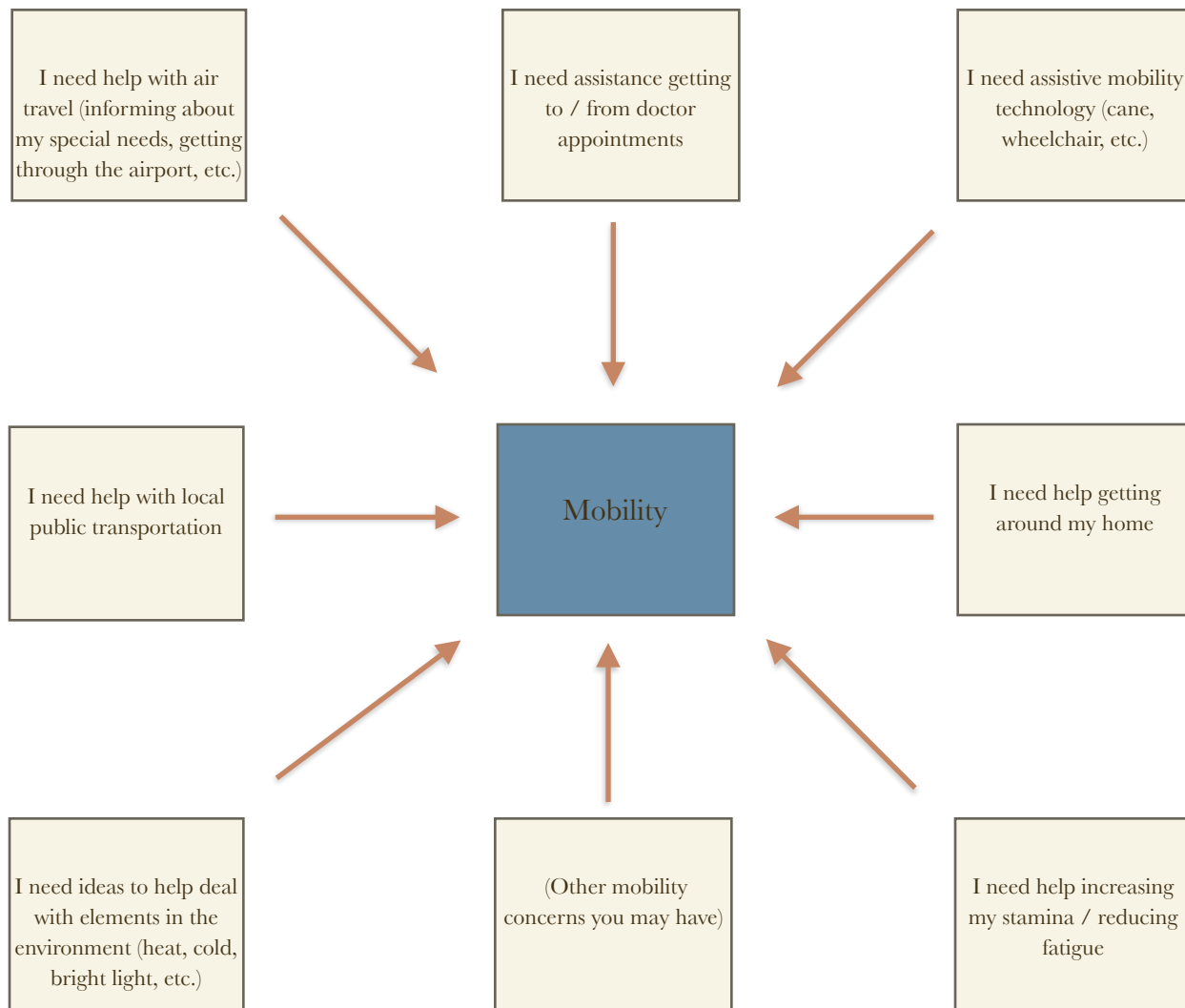
If traveling to a local appointment, reliable transportation either with public transportation, or from a friend, family member, or other caregiver must be secured.

If traveling by air, transportation to the airport needs to be set up, notification to the airline about any special needs has to be made, safe and speedy navigation through airport security needs to be assured, and upon arrival at the destination a reliable pick up has to be scheduled in advance.

In addition, constraints such as fatigue, time of day, and sensitivity to environmental elements such as heat, cold, and sunlight all have to be taken into account.

These are just a few simple examples of mobility issues that brain tumor survivors have to deal with. I am confident that every survivor has faced these or other similar challenges, whether great or small, at one time or another.

The diagram on the following page shows various issues survivors may have in terms of mobility. If you are having trouble in a certain area, simply take this diagram to a member of your health care team and point to or circle the area (or areas) that are troubling you, and they should help you.



Inclusion

Inclusion, for the purpose of this paper, is accommodating the needs of the least among us.

Of all the factors influencing quality of life for brain tumor survivors, inclusion requires the most subtle discernment and sensitivity on the part of all the people in the life of the survivor, from friends and family to those in the medical community; it's also the most elusive for survivors not only because they are isolated from so many things which others take for granted, but also because they lack a common voice with which to be heard and understood.

Friends and family and those in the medical community must extend themselves with *overwhelming* effort by recognizing, acknowledging, and accepting limitations; making flexible plans for family gatherings; holding social get-togethers at home; being patient and really listening during appointments; learning and understanding what the survivor and caregiver are going through; arranging for participation in the educational system, or religious or spiritual gatherings (and so on and so on).

This effort will not only serve to include brain tumor survivors in more and more life activities and decision making, it will also take a tremendous burden off caregivers (who often times take the impact when life somehow excludes their loved one) thus increasing the quality of life for all involved.

And in the words of the Institute of Medicine (*yet again*), “Patients and caregivers deserve no less.”

The diagram on the following page shows various challenges survivors may face in terms of inclusion. If you are having trouble in a certain area, simply take this diagram to a member of your health care team and point to or circle the area (or areas) that are troubling you, and they should help you.

