

**About:** If you have found your way to this site, then I hope you will be able to glean some information to assist you with the difficult task of assisting a loved one that struggles with TBI.

One of our loved ones struggles with TBI due to a vehicle accident that first left our loved one in a coma for nearly 4 weeks and then required skilled nursing assistance for another 4 weeks. Once we made the decision to bring our loved home, we were faced with making many decisions. The best advice that we can give you is to never give up, regardless of the diagnosis your loved one is facing. While there are many factors that play into a possible recovery scenario, one of them being age and previous lifestyle, there is always "Hope". We were told "this is as good as it gets", when our loved one came home, but we were not willing to accept that. Our loved one had a very severe TBI injury, five inoperable sub-cranial bleeds, as well as the fact that there was the situation of having been on life support for over 3 weeks, which contributed to further decline of the brain.

Our loved one is a success story. Our loved one has recovered through many stages of a traumatic brain injury and is now very cognitive and working on a degree in Sociology. While still in a wheelchair, and facing spastic paralysis issues, as well as short-term memory loss, our loved one works on physical and cognitive capabilities every day. It has taken nearly 3 years to get to this point and we are not done yet. We have no doubt that our loved one will continue to grow and improve!

Please remember that we are not professionals, just a mom and dad who have been through the process of assisting with recovery. Each situation is different, and this site is geared to finding the help you might need. We are not experts!

## WHAT IS TBI?

A head injury that causes damage to the brain by external force or mechanism. It causes long term complications or death. It occurs due to bumps, blows, jolts or any other head injury, and causes temporary or permanent damage to the brain. This type of injury requires rapid diagnosis.

Facts: Treatable by a medical professional. Diagnosed by medical professional. Requires lab test or imaging. Urgent medical attention necessary. Can last several years or be lifelong. Can be dangerous or life threatening if untreated<sup>1</sup>.

## **FIRST THINGS FIRST!**

*Be your loved one's advocate, but don't get angry with medical professionals!*

Just a few days after our loved one's accident, we were asked to have a meeting with his assigned medical staff at the hospital. His situation was not very promising, and we were asked if we knew if he was an organ donor. This is a very hard thing to be approached with when you are confused, upset, and stressed. When our loved one left the hospital to stay at a skilled nursing facility we were told by the neurologist "This is as good as it gets!". At the skilled nursing facility, we faced many challenges with some of the medical professionals and were asked by a pulmonologist "Is this all he does?", because he was not familiar with our loved one's condition outside of his own expertise. When we pulled our loved one out of the skilled nursing facility to bring him home, the comment was "Take good care of him!". All of these comments upset us greatly. So, if something like this happens to you, just know that it is not directed at YOU. These facilities are understaffed, individuals, just like you, are also stressed, overworked, and have a huge amount of responsibility on their shoulders. Don't take it personal! Move on ... make up your own mind about your loved one!

*What is the short-term prognosis? / What is the long-term prognosis?*

Much will depend on the type of treatment and recovery needed by your loved one. This, of course, depends on the severity of the TBI. You will need to assess this situation early on.

Medical Insurance: Does our loved one have insurance? Even though this is mandatory now, many individuals still do not carry medical coverage. If your loved one does not have insurance, immediately apply for Medicaid (some states use a different name.) Your first step will be to contact the social services office in your location and submit the information needed. Be prepared to encounter long waiting times and lots of paperwork. Inform yourself as to what you need to bring with you beforehand.

If your loved one has medical insurance, will it be sufficient to accomplish everything you hope to achieve? If you are in a position to do it, add an additional policy immediately! This is especially true if you are looking at skilled nursing facilities and neurological clinics. Find out what medical insurance companies they

work with and go from there. You'll find some information on primary and secondary insurance on this website.

Medical insurance will dictate in many ways what help you will be able to receive! Always fight for the best you can get! Be willing to reach out to organizations that offer free or low-cost assistance! Set up a "Go-Fund-Me" page if you need to. Don't accept the status quo! Be prepared to make many calls to the insurance carrier, facilities, doctors, and case workers. This seems overwhelming at first, but you'll quickly get into the groove and learn to assert yourself as an advocate for your loved one when necessary. If you are in a position to do it, add an additional policy immediately! You'll find some information on primary and secondary insurance on this website.

Medical Power of Attorney: Does your loved one have a "Medical Power of Attorney"? A medical power of attorney allows a person to specify who will make medical decisions for them if they are incapacitated. However, once they are incapacitated, they can no longer grant a power of attorney. (Freewill.2023)<sup>ii</sup>

Medical Directive: Does your loved one have a "Medical Directive"? A medical directive is a legal document that contains instructions to be followed regarding a person's health care decisions if they become incapacitated. The directive will name a person (persons) that can make medical decisions on their behalf. This type of legal document also contains decisions the person may have made beforehand, for example, a request that the person not be resuscitated. As with a medical power of attorney, this document cannot be created after a person becomes incapacitated. Other names for this document are: living will, instruction directive, advance healthcare directive, power of attorney for healthcare, or healthcare proxy. (National Institute on Aging. 2023.)<sup>iii</sup>

Medical Guardianship / Conservatorship: If your loved one does not have a "Medical Power of Attorney" or a "Medical Directive", it might be necessary to obtain a "Medical Guardianship". This type of guardianship can be temporary or permanent. Many people shy away from this type of control because they fear that they will be responsible for everything that concerns their loved one. Guardianships/ Conservatorships can be tailored to your needs and can be set up to cover medical decisions only. Some states restrict the guardian's ability to sign off on mental health treatment for the loved one, while others allow it. Your loved one's physician or psychiatrist will be able to advise you further on this matter. In most

jurisdictions, free help is available to work through the maze of documents that need to be prepared and filed with the court. If you are able to, consult with an attorney on this matter, as court assistive programs can only advise on information that needs to be provided, they cannot advise you on the legality of certain issues you must agree to and sign off on. This type of court proceeding will always require assessment by professionals! Get your doctors involved, as they have to prepare statements and sign off on same. The court will most likely involve a court appointed social worker to work with you as well. This process can take a while, but if you are facing a long-term recovery, it is very worthwhile to obtain guardianship / conservatorship to make decision making easier. (Family & Aging Law Center. 2018.)<sup>iv</sup>

### Supplemental Social Security Income (SSI)

If you are in a position where your loved one will have a longer recovery and is unable to work, begin the process of applying for Supplements Social Security Income. This can be a long process with affidavits needed from doctors and professionals. There are several steps to be completed, which all include many forms and paperwork. It can take over 12 months to see your first supplemental income check. So, if you feel your loved one qualifies, start early. Get started by downloading forms at [SSA.Gov/ssi](https://www.ssa.gov/ssi) and then make an appointment at your nearest Social Security Office. (SSA.Gov. 2023.)<sup>v</sup>

### If you have made the decision to let a health facility take care of the recovery process, or perhaps a long-term care taking situation:

Check out the facilities yourself. Look for the following;

- Is the facility secure?
- Are the patients clean in appearance?
- Are patients treated with dignity and respect?
- Are patients restrained?
- Are patients' facilities and rooms clean?
- How much staff is available and what type of staff?
- Are patients treated with a sense of purpose? Are therapists available at the facility to facilitate daily therapy? (Physical Therapy (PT), Occupational Therapy (OT), Speech Therapy (ST)).

Get the best you are able to get with what you can work with (insurance, finances). (Marquette. 2023.)<sup>vi</sup>

*If you have made the decision to bring your loved one home:*

If you've made the decision to bring your loved one home at some stage of the recovery process, prepare immediately. Don't wait! Here are some points to help you with that. Work with doctors and medical professionals on equipment needed. The needs should be provided in the facilities release documentation as well, but you will need to have things in place before your loved one comes home.

Physical needs - you will need a prescription for each piece of medical equipment needed to take care of your loved one. The releasing facility should be able to prescribe items through your loved one's case worker.

- Is a wheelchair needed? - TBI patients may have the need for a wheelchair due to limited mobility.
- Is a medical bed needed? - TBI patients may have a need for this due to limited mobility
- Is a hoist lift needed? - Some TBI patients need a lift to assist with physical tasks due to limited mobility.
- Is a transfer chair needed? - Some TBI patients may need a transfer chair to be able to get into a bathtub or shower due to limited mobility.
- Is a commode chair needed? - Some TBI patients may need a commode chair due to mobility issues.
- Is a dental suction machine needed? - Some TBI patients are unable to brush their teeth on their own, as well as they may have problems with swallowing.
- What medicines are needed? - Ensure that prescriptions are preapproved by the insurance and transferred to the pharmacy ahead of time, so they are available when you need them.
- Is transportation needed? - TBI patients often have mobility issues and are unable to enter or exit a vehicle to get to medical appointments. Medicaid will often

assist with this task, as will some medical insurance companies. Many cities have "free transport assistance" provided by parks and recreation districts. If you feel you will need assistance in this manner, prepare your authorizations ahead of time. Things can quickly become difficult if transportation becomes an issue. Not everyone can afford a van that can fit a wheelchair and ramp! Consider applying for a temporary Disability Plaque through your DMV as soon as possible. You will need a statement from your doctor with the appropriate DMV forms.

- Assistive needs? -

Does your loved one need a health nurse check up on a regular basis? Does your loved one need wound care (bed sores.) Ensure that these items are specified by the facilities case worker and arranged ahead of time.

- Therapy needs? -

Your loved one may have the need for a variety of therapies. Physical therapy, occupational therapy, speech therapy. What type of therapy will he be able to receive at home or at a facility? Ensure that therapy options are discussed before your loved one's release and arranged prior to the release.

Most likely you will need to exercise with your loved one, or at the minimum assist with exercise, to ensure mobility and prevent atrophy. (See medical terms for more information.) Make sure you know what is appropriate at the time of his release and continue to discuss with therapists to also assist with recovery when they are not working with him. Remember, they will most likely only provide limited therapy and it will be up to you to continue where they left off. (See exercise information.)

Emotional needs TBI patients go through phases of recovery and each stage of this recovery is marked by certain behaviors. The more severe the brain injury, the more of the stages will be encountered as your loved one tries to regain cognitive and physical functions. This recovery scale is called "Rancho Scale" I'll describe it in more detail in the resources area. Stages are usually identified by a speech therapist or speech pathologist and this medical professional can give you more insight on what you can do to assist.

Cognitive needs As your loved one goes through stages of rehabilitation there will need to be ongoing cognitive therapy as well. Let therapists guide you and get as much information as possible. This will be a continual effort as therapy evolves and changes. Become "friends" with dollar stores, thrift stores, and websites that provide free cognitive worksheets. Start collecting safe, plastic recyclables for "thinking outside-of-the-box" activities. These will all be your best resources. (Also check out the Resources Tab.)

*If your loved one is at home: Get Help!*      *Get help, don't face this battle alone!*

Health insurance companies have assistive programs for home nurses, social services, and in-home therapies. Take what you are able to receive!

Some states have "In-Home Health Care Assistive Programs". These programs provide an "In-Home Health Care Provider" at no cost to the patient to assist with daily supervision and care taking of a loved one. Programs work with a social worker to assess how many hours a week a provider can give care. If your state allows for this type of assistance, apply as soon as your loved one comes home! An assessment by a social worker and a clinical nurse is usually required and medical documentation must be provided.

Accept help from outsiders, friends, and family members! Don't be too proud to accept assistance! Taking care of a loved may not seem as much, but it can be very taxing! If you are a church member, reach out to your congregation. Even a simple meal provided by someone else, or an offer to assist with travel needed to a doctor's office, can make a very big difference in your life! Burnout is a huge factor in your loved one's recovery. He /she depends on you, your strength, and your expertise.

*Educate Yourself!* Whatever the level of brain injury your loved one is facing, educate yourself. This website has a listing of many reputable websites that provide great fact sheets, home therapies, and situational information. The saying

“Knowledge is Power” is definitely true when dealing with TBI. Learning about what your loved one is facing will help you understand what type of therapy is needed, as well as how you can aid the recovery at home! (See the Resources Tab for more information.)

---

<sup>i</sup> Karthikeya T M. 2016. “Traumatic Brain Injury”. Retrieved September 19, 2023. [https://www.msn.com/en-us/health/condition/traumatic-brain-injury/hp-traumatic-brain-injury?source=bing\\_condition](https://www.msn.com/en-us/health/condition/traumatic-brain-injury/hp-traumatic-brain-injury?source=bing_condition)

<sup>ii</sup> Freewill. 2023. “What Is A Medical Power of Attorney?”. Retrieved September 5, 2023.

<sup>iii</sup> National Institute on Aging. 2023. “Advance Care Planning: Advance Directives for Health Care”. Retrieved September 5, 2023.

<sup>iv</sup> Family & Aging Law Center. 2018. “What you need to Know About ... Guardianships & Health Care Powers of Attorney”. Retrieved September 5, 2023.

<sup>v</sup> Social Security Administration. 2023. “Supplemental Security Income (SSI)”. Retrieved September 5, 2023.

<sup>vi</sup> M. Marquette. 2023. “7 Key Traits of a Strong Skilled Nursing Program”. Retrieved September 5, 2023.