

## **WHAT MAKES IT SO HARD TO GET EXPERT HEAD INJURY TREATMENT**

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In the guides we provide on this Web site, and in others written by other head injury specialists, you will find warnings about how hard it is to find expert care and treatment for people with head injuries. These warnings are unusual--you don't see them being posted for most other disorders. In this document, I offer my own explanation of the factors I believe to make expertise in head injury so hard, and so important, to find.

### A. Head Injury is a Unique Clinical Problem With Unique Clinical Needs

Head injury has only been recognized in the clinical world of rehabilitation as a specialty area for about 25 years. Consequently, there are no professional training programs in head injury. No one leaves graduate school or medical school trained in this disorder. Only a few graduates each year have the opportunity to intern or to do post-doctoral training in a facility specializing in head injury.

Because head injury is such a new area of specialty, and because there is almost no quality control for head-injury programs, even among those programs specializing in head injury there is a tremendous variation in program quality. The only standard that exists for quality assurance is certification by the Commission on the Accreditation of Rehabilitation Facilities (also known as CARF). CARF sends multiple-expert survey teams to inspect facilities, and requires them to meet a catalogue of disorder-specific program requirements and standards. The surveys are extremely thorough and the standards are tough. My programs have been through (and passed) 5 surveys, and I trust CARF certification as an assurance of program quality. However, historically, most self-advertised head injury specialty programs have not obtained CARF certification.

### B. Training to Treat Other Disorders Doesn't Get the Job Done

Many facilities and individual clinicians are trained in programs that offer a curriculum for the treatment of brain disorders as a group, or behavior disorders as a group. These programs, and the professional bodies that the graduates join, claim expertise on all forms of brain or behavior disorder, and they do not warn their students or the public that their training does not produce expertise with specific disorders such as head injury. So most neurologists, neuropsychologists, clinical psychologists, social workers, rehabilitation counselors, speech-language pathologists, occupational therapists and physical therapists believe that they are qualified to treat patients with head injuries. They have been told by their teachers and their schools that they are qualified, and their license and their association membership indicates that they are qualified to treat everyone in the larger group. So most people receive non-expert treatment from well-meaning professionals who do not know the extent of their own limitations.

What happens when a professional person with general training for that discipline tries to treat a person with a head injury? Not much. Since they are not trained in the use of tools specifically designed for head injury, and usually don't even know that specialized tools exist, they almost always use the tools in which they were trained, which were developed for other disorders.

### 1. Physicians: Neurologists

Neurologists are the physicians most likely to have received some training in TBI. However, neurology is a diagnostic specialty, not a treatment specialty. So the neurologist is most of ten the one who diagnoses the injury. Neurologists also have tests to detect complications of head injuries, some of which are life-threatening. So you are fortunate to come under the care of a neurologist. However, they do not have any tools or techniques to treat the direct effects of brain damage. They also know relatively little about how this treatment is done, although they may not realize the extent of their lack of knowledge in this area.

### 2. Physicians: Psychiatrists

Psychiatrists usually take a class on brain disorders in medical school, and treat a few patients with brain diseases during their residency, but rarely more than that. But their board exams are given to both psychiatrists and neurologists, so they must demonstrate book smarts about brain disorders in general. The diagnostic bible in psychiatry also has categories for diagnosing brain disorders, although no brain injury specialist ever uses those categories because they are wack. Consequently, psychiatrists believe that they are fully qualified to treat all sorts of brain disorders including TBI.

Psychiatrists of the last century often did psychotherapy with their patients. Today's psychiatrists almost always limit their practice to prescribing drugs. When a patient with TBI falls into the hands of a psychiatrist, there is a risk that unnecessary and even harmful drugs may be prescribed. For example, many brain injured patients show a variety of symptoms in common with depressed patients (complaining, upset, passive, flat voice, lack of facial expression, lack of initiation, poorly controlled crying) without being depressed at all. But I have seen many of these patients put on anti-depressant drugs by physicians. When the prescription is cancelled, the patient does not get worse, suggesting that the drug was not necessary in the first place. Many head injury patients also go through a phase of disoriented agitation which is a natural part of recovery. Psychiatrists have drugs they use to control the behavior of agitated psychotic patients, but when they give these drugs to head injury patients, recovery stops. Head injury specialists discovered that placing these patients on quiet wards in single rooms, with soft furniture (including all-mattress beds designed at Craig Hospital in Colorado) allows them to pass through this phase quickly; no drugs are needed. Psychiatry is a methodology for mental illness, not brain disorder. Occasionally, a mentally ill patient gets a head injury and needs help from a psychiatrist, but this is not the case for most patients. A handful of psychiatrists have become head injury experts, and they tend to make very little use of drugs. They are more prone to just keep an eye on recovery.

### 3. Physicians: Psychiatrists

This odd name is the designation for medical doctors who specialize in sports medicine and/or rehabilitation. The old school doctors with this specialty were experts on physical injuries and physical rehabilitation therapies. They often directed rehabilitation units and stand-alone rehabilitation hospitals, although they are relatively few in number and so there are not enough to go around to fill every rehab job. When head injury programs became a popular, money-making addition to rehabilitation hospitals, many of these doctors took charge of the treatment of head injury patients. In many ways, this was unfortunate. Physical rehabilitation techniques, approaches, and philosophy generally work poorly with TBI patients. Even techniques that serve stroke patients reasonably well don't work with TBI patients. So in many cases the treatment was directed by someone who was not trained to do it, and not aware of the methods that proved effective.

There is a second generation of younger psychiatrists who trained at medical schools, internships, residencies, or post-graduate fellowships at the hospitals that provide fully specialized head injury treatment (for example, Santa Clara Valley Medical Center in California, Barrow Neurologic Institute in Phoenix, TIRRR in Texas, Moss Rehabilitation Hospital in Philadelphia, Robert Wood Johnson Rehabilitation Hospital in New Jersey, Rusk Institute at New York University, Mount Sinai Hospital in New York, and Braintree Hospital in Boston). These physicians sometimes come away from their training with expertise in TBI, and can be a valuable resource in planning a recovery program. However, very few physicians fit this description, and most cities do not have one.

### 4. Physicians: Family Practice and Other Specialties

Most physicians are not trained in the specialty aspects of head injury. However, managed care requires these physicians to take charge of the care of all patients. This practice often makes it difficult to get specialized services for TBI authorized, as neither the primary physician nor the insurance carrier is aware of the need for specialized care.

### 5. Neuropsychologists

Neuropsychology is a legally uncontrolled term. Laws and regulations require only that the individual who claims to be a neuropsychologist is licensed as a psychologist, which may mean that his/her formal training was limited to any one of the psychological specialty areas, including research. The only way to determine the extent to which a self-titled neuropsychologist is qualified is to investigate that professional's education and qualifications. The most visible qualification is certification by the American Board of Professional Psychology (ABPP), which identifies the diplomate as a qualified specialist. Some psychologists are qualified in diagnosis and testing (by the Boards of Clinical Neuropsychology and/or Professional Neuropsychology) while others are qualified in evaluation and treatment (by the Board of Rehabilitation Psychology).

Even among neuropsychologists who present appropriate qualifications, there are very few treatment specialists. Most neuropsychologists are trained in evaluation of brain injuries, but not in treatment. Of those who are trained in treatment, the overwhelming majority are trained to do psychotherapy, but not to treat cognitive disorders. Furthermore, by tradition, neuropsychologists who have no training in treatment of cognitive disorders make recommendations for treatment, often having no other basis for the recommendation than their common sense. Such recommendations should not be regarded as expert work products.

A very small group of neuropsychologists designed and directed programs for traumatic brain injury. Most of the influential pioneers in the specialty are individuals with this background. The most influential single individual in the history of the field is probably the Russian program director, A. R. Luria, who began his career as a psychologist. The group of specialists who laid the groundwork for modern brain injury rehabilitation, at Rusk Institute at NYU, and the treatment team that invented the high-impact, "gold standard" form of TBI rehabilitation (called holistic cognitive rehabilitation) was composed entirely of neuropsychologists and psychologists. The references provided in the documents on this Web site list the names of most of the influential expert neuropsychologists of the present generation. However, this substantial, if brief, tradition of innovation and leadership in the field should not lead consumers to believe that their local neuropsychologist is competent to treat or recommend treatment for TBI.

#### 6. Psychotherapists (Clinical Psychologists, Counselors, Social Workers, etc.)

Just as the vast majority of physicians and neuropsychologists have no specialist training in TBI, so psychotherapists from the various disciplines tend to have no specific training in dealing with this disorder. In fact, traditional psychotherapy training often warned that long-term psychotherapy is ineffective and should not be used with TBI, and recent experience by specialists continues to agree with that opinion. On the other hand, many psychotherapists are trained to regard their practice as applicable to everyone, and they may undertake to treat a person with a head injury with the best of intentions.

There are many forms of psychotherapy, and they can be quite different. Most of the traditional forms of exploratory psychotherapy are based on the assumption that we are the cause of our own problems, mainly because of abnormalities in motivation and attitude. When this approach is used in treating a patient with TBI, the search for psychological causes comes up empty handed, while the therapist does not deal with the real cause of the person's problems at all.

There are several kinds of psychotherapy that are based on behavior modification, a procedure developed by studying animal behavior and then applied successfully to many human psychological disorders. Behaviorism assumes that problems are caused by a faulty learning history, an assumption which again does not fit the facts in TBI. Forms of behavioral treatment developed by non-specialists in TBI are ideal for treating bad habits or problems in using well-learned skills. Unfortunately, TBI patients tend to have

the fewest problems in this area. There have been brilliant forms of behavior modification developed by Donald Meichenbaum, Rodger Wood, and other specialists in TBI, but mental health therapists are rarely familiar with them or qualified to perform them.

Some kinds of psychotherapy can be helpful to survivors, but not in dealing with the main problems produced by the injury. When a survivor has developed a true mental health problem with anxiety or depression, cognitive-behavioral psychotherapy can be quite helpful. Humanistic psychotherapy or counseling is sometimes helpful simply by providing support and encouragement, and therapists endowed with unusually strong common sense can sometimes help in solving practical problems that come out of living in the World of Head Injury. Finally, highly successful recoverers often uncover pre-existing psychological conflicts that were not causing them serious problems before the injury, but are now blocking their progress in advanced recovery. For them, psychotherapy can be an excellent add-on that helps them to maximize their total psychological health.

#### 7. Physical Rehabilitation Therapists (Speech-:Language Pathologists, Occupational Therapists, Physical Therapists)

Most survivors who receive real therapy during the early months of recovery are sent to a physical rehabilitation unit or clinic where they are seen by therapists of all three of these disciplines. Unfortunately, these therapists almost never have training in or knowledge of the therapies that were designed for TBI, let alone the ones that have demonstrated the greatest effectiveness.

As with the physicians and psychologists, the therapists of these disciplines are usually trained in a single, general approach to brain or behavior disorders that simply does not meet the needs of the TBI patient. In the 1940's through the 1970's, TBI survivors were sent to general rehabilitation units with strikingly unsatisfactory results. Unlike most stroke and brain tumor patients, head injury patients turned out to be disruptive and hard to manage. Most brain disorder patients are relatively passive and cooperative, whereas TBI patients don't take orders well and don't believe that therapy is necessary or appropriate for them personally. Moreover, the exercises used as the basis for physical rehabilitation therapies proved to be ineffective, having little long-term benefit for TBI patients.

Why doesn't "stroke rehabilitation" work on head injuries? Most stroke patients are suffering from concentrated damage to the brain systems that are used to operate their well-learned skills, while the brain systems that organize and supervise behavior are untouched by the illness. Therapists simply measure the set of basic mental skills, and help the patients to practice using the ones that are defective. Because the American medical system brings these patients into therapy as early as possible, all brain disorder patients are suffering from a combination of short-term, temporary symptoms and long-term, permanent symptoms, including the head injury patients. Physical rehabilitation therapies produce improvements in the skills that are treated, but many rehabilitation scientists believe that these improvements would have taken place anyway simply

through the passage of time. In other words, they believe that these therapies only improve the temporary impairments, not the permanent ones. Even the research on stroke patients is unconvincing, and there is no body of evidence suggesting that these exercises do anything remotely helpful for long-term recovery from TBI. When children leave the hospital and return to school, if the school even recognizes that they are having special problems, they simply get more therapy of this kind. The nationally recognized specialists in TBI are in agreement that this kind of therapy is unproven and appears to be fundamentally the wrong approach, even though it is the main therapy people receive.

Sadly, this is not the bad news. The bad news is that head injury therapy became a huge fad in the late 1980's, attractive to hospital administrators because it racked up higher charges than mainstream rehabilitation. To capitalize on the money-making potential, rehab hospitals and venture capitalists opened up more than a thousand new self-titled "head injury" or "cognitive rehabilitation" programs over the next ten years. Since there were so few real experts in genuine specialized TBI therapy, and the specialized therapy was complicated and hard to learn, almost all of these programs were put together by assembling a group of physical rehabilitation therapists and assigning them to make a curriculum of physical rehabilitation therapies. However, this left the customers of these bogus programs believing that they were getting expert therapy, and the therapists who served in them believing that they had become TBI experts. Even though managed care has shut down most of these programs, hospitals in most cities offer something they call head injury therapy using the leftovers from these failed programs. One safeguard when looking for head injury therapy is to ask about CARF certification in TBI. Some of these programs are CARF certified in general rehabilitation, but a physical rehabilitation program dressed up as TBI therapy cannot get certified in TBI by CARF.

## 8. Schools

The research indicates that severe TBI produces permanent educational disability, and that without effective treatment most children end up as unemployed, unproductive, and behaviorally maladjusted adults. A federal law passed in 1990, and renewed each time it came up for review, requires the schools to identify these children and to provide them with specialized therapies. However, Congress never even tried to pass enough funding to make it possible to implement this wonderful law, so it doesn't get followed in any school I have ever seen. The state and national statistics indicate that roughly one in every hundred children with educationally disabling TBI is actually classified as such. Even when students are classified, they normally receive treatments designed for learning disabilities, which resemble stroke therapy in many ways and are known to be ineffective for TBI. Experts on pediatric TBI rehabilitation have been calling for specialized programs in the schools for more than 25 years, but those calls have not been answered.

## 9. Home-Brew Treatments

Our research, while it is limited, indicates that survivors do not recover at all when they are left on their own, with whatever help the family and the community provide. I have known many families who put their heart and soul into trying to help,

only to give up in defeat and despair years later. The problems of head injury, and the solutions to those problems, seem to run counter to common sense and to be hidden from ordinary intelligence and reasoning. If it sounds like I am claiming that it takes genius to figure out how to treat a head injury, that is far from the truth. But it does take thinking entirely out of the box, and most people, no matter how hard they try, seem not to figure it out on their own.

The most common approach that most parents take to trying to aid recovery is a kind of "re-parenting." The behavior of survivors resembles the behavior of children and adolescents in certain ways. So parents tend to put their approach into reverse and try treating the survivor as they did in his/her youth. This means correcting bad behavior, which has no recovery value. It means hinting at the behaviors than need to be used in a situation, which has no recovery value. Some parents try rewards and punishments, which also have no recovery value most of the time. Some parents even try getting out school books from elementary school and trying to "re-teach" their adult survivors the academic skills of a child. This not only has no recovery value, but it discourages or infuriates most of the survivors.

Many parents also try to deal with TBI as if it were a normal problem of adulthood, like those experienced by people who have other serious illnesses and injuries. They try to be supportive and encouraging, which in itself has no recovery value. They relax the rules and allow the survivor an extended period of reduced duties and expectations, which tends to make problems worse. They beg their children to turn to religious faith, and pray for miraculous recovery, but in my 27 years working with survivors, I have not yet seen one miraculous recovery through prayer alone.

The closest thing to a natural solution that I see fairly often is a technique that many retired spouses and doting mothers use. They become the survivor's constant companion, do everything together, and provide kindly and loving guidance for every step. This works very well for those survivors who are comfortable being so dependent. But this is, of course, a very limited solution.

Finally, I have met a small number of people who have developed good recoveries on their own. I have not, nor has anyone at this point, performed any research on these natural recoveries, so any comments I offer are strictly my personal opinion. It is my impression that the people who have these natural recoveries are tough, highly responsible, humble, persistent, and willing to doubt their own natural reactions. This is a pretty unusual combination of personality characteristics, which may explain why these recoveries are so rare. This makes a little more sense because the people who make the best recoveries through expert therapy have similar characteristics.

#### D. CONCLUSIONS AND RECOMMENDATIONS

If you have, or can get, \$60,000-110,000 (in 2007 dollars) to pay for treatment, plus money to pay for your living expenses, and you are willing to devote between 5 and 11 months to recovery, I would recommend that you go to New York University to

receive therapy at America's oldest and most recognized holistic cognitive rehabilitation program, under the direction of Dr. Yehuda Ben-Yishay. If you are in the vicinity of Phoenix, Arizona, go to Barrow Neurologic Institute and talk to Dr. George Prigatano, who may be able to arrange therapy at a slightly lower rate. If you are in Minnesota, talk to Dr. James Malec at the Mayo Clinic. Those are three places where you can still get the gold-standard therapy provided by a top-notch staff under the guidance of one of the world's living experts.

For most people, that is simply not an option. If you have about five thousand dollars gathering dust on your mantle piece, you might want to consider getting a neuropsychological evaluation from one of the TBI experts whose work is cited in this chapter and other chapters posted on this Web site. At least you could get a well-reasoned and scientifically based set of personalized recommendations for recovery.

If you are not independently wealthy or supported by some unusually generous form of insurance or medical care program, get the most expert therapy you can find. That means checking out the credentials of the people from whom you are free to choose. If you have the opportunity to get to someone who has worked in a truly specialized, cutting-edge center, by all means do so, even if it means having to drive some distance to get there. If all you have available is non-specialized care, which is the case for most survivors in the United States today, get as much of that therapy as you can. But be sure to realize that it is unlikely to provide all of the ingredients needed to make up a good recovery.

The unavoidable conclusion is that most Americans who have been thrust into the World of Head Injury need to learn the rules of that world on their own. Since there is no substitute for training yourself, you should begin as soon as possible. As you read about TBI, you will find that there is a consensus among the national experts about what is wrong and what seems to aid recovery. So seek out the writings of those experts, and put them into practice as well as you can. It is your best shot.

At GiveBack, our philosophy is to band together and to help one another with this horrendous task. Working on recovery as a group seems to make it less intimidating. Nothing makes it easy. The most central fact about recovery that we have learned from studying head injuries is that recovery is a long, tough journey. The first step in taking a long, tough journey is to get the road map.

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