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Brain Injury Alliance of New Jersey

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Helpline: 1-800-669-4323
www.bianj.org

No Brain Injury is Too Mild to Ignore, or Too Severe to Lose Hope

Selecting a Rehabilitation Facility

By Garry Prowe

Selecting a rehab facility is a crucial decision. It should not be rushed. There are hundreds of rehabilitation programs. They vary considerably in the philosophy, quality, and variety of the services they offer. I was in no condition—physically or mentally—to carefully research, visit, and compare rehab facilities. I relied heavily on my sister Barbara to handle this. You may want to ask someone to help you with this time-consuming job.

To start your search, compile a list of rehabilitation facilities to consider. Ask for recommendations from the following folks:

- The hospital social worker or case manager
- The physicians treating your survivor
- Your family doctor
- Your health insurance company, as your choices may be limited by your policy
- Your state brain injury association
- Families with rehab experience
- The Brain Injury Association of America has an online searchable database which includes a list of rehab programs (800-444-6443 & www.biausa.org).
- If your employer offers an Employee Assistance Program (EAP) or a Life Events Benefit, it may include Adult / Elder Resource and Referral Services, which may help you identify facilities in your area or elsewhere.

I believe that one factor—proximity to your home—is paramount in the selection of a rehabilitation facility. As I wrote earlier, support from family and friends during rehab is an invaluable motivator for the survivor. If the rehab facility is close to home, this support role can be shared. If it's far from home, supporting the individual typically falls on just one person—usually Mom—or no one at all.

It also is easier to participate in decisions to be made about your survivor's care and to monitor the way she is treated at the rehab facility, if it's convenient for you to be there frequently. The choice of a rehabilitation program, however, should not be based solely on location. Some folks who live in more rural areas have no choice but to travel a long way to a rehab facility.

To help you begin your selection process, here's a list of fourteen services every brain injury rehab program should have:

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1. Evaluation and assessment of the patient's unique physical, cognitive, communication, emotional, behavioral, and social impairments
2. Physical therapy to regain mobility, strength, balance, coordination, and endurance
3. Occupational therapy to relearn self-care and daily living skills
4. Speech and language therapy to treat communication and swallowing disorders
5. Cognitive rehabilitation to treat deficits in attention, concentration, memory, problem-solving, planning, and decision-making
6. Neuropsychology or rehabilitation psychology to help the survivor accept the consequences of her injury and to treat any emotional and behavioral problems
7. A social skills group to relearn how to interact with others
8. Recreational therapy to relearn leisure skills and, maybe, develop new interests
9. Access to other medical specialists, such as neurologists, orthopedists, and pain management doctors, to provide treatment for other medical problems
10. Education for both the patient and the family in living with a brain injury
11. Family counseling to help everyone adjust to their survivor's impairments
12. Substance abuse counseling
13. Trips outside the rehab center to reacquaint the survivor with the community and to determine any special needs
14. Vocational therapy to help higher-functioning survivors return to work

All staff members should be well trained and experienced in treating people with brain injuries. If the facility uses students, interns, or less experienced therapists, they should be monitored closely by seasoned practitioners. The staff of a rehabilitation facility should include:

- A board certified physiatrist or neurologist as the team leader
- A neuropsychologist or a rehabilitation psychologist
- Physical, occupational, speech, recreational, and vocational therapists
- A rehabilitation nurse who will assist the patient with her therapy homework in the evening and on weekends
- A clinical dietitian, as survivors often have little appetite when they begin rehab
- A case manager who will negotiate with your health insurer the duration of your survivor's therapy

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When evaluating rehabilitation facilities, it's best to visit at least twice, the first time with an appointment, the second time unannounced.

Here are ten things to look for as you inspect the facility:

1. Cleanliness
2. Adequate space for many different types of therapy
3. Staff professionalism, attention, and compassion for their patients
4. Openness: Do you feel welcome observing activities, walking around, and asking questions?
5. Are the patients clean and well kept?
6. Do they appear content with their treatment?
7. Is the food appealing?
8. Is there a home orientation suite, which enables the patient to practice skills in a home setting?
9. Do you feel rushed or pressured?
10. Are there conveniences for families, such as a cafeteria, meditation room, clergy, and lounges?

Don't be swayed by how nice the facilities appear or how wonderful a brochure looks. Ask questions. Record the answers so you can compare facilities later. Consider using a tape player to record conversations and your impressions of the facility. Also, don't be shy about approaching families with patients at the facility. They are valuable sources of information. Here are some questions to ask:

The Rehabilitation Program

• How long has the program existed?
• Is the program CARF-accredited? The Commission on Accreditation of Rehabilitation Facilities (CARF) sets quality standards for rehab programs. If the program isn't accredited, be wary and ask why not. You can obtain a list of CARF-accredited providers by calling 866-888-1122 or at www.carf.org.
• What is the staff-to-patient ratio?
• Are special accommodations made for special populations, such as children, seniors, and drug and alcohol abusers?
• How many people with brain injuries has the facility treated?
• How many people does the facility treat at one time?
• What is the average length of stay?
• Who determines the length of stay?
• How flexible is the program? We were very disappointed with our program's lack of flexibility. Jessica was anxious to improve her soft and halting speech. But her request for more speech therapy and less recreational therapy—which she felt was a waste of time—could not be accommodated.

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• Does the program maintain records on patient outcomes?
• Does the facility provide outpatient rehabilitation? This allows for a smooth transition from inpatient to outpatient therapy, which is helpful since you and your survivor will be coping with many other issues when she returns home.
• How often will you be able to speak to the doctor who heads your patient's treatment team?
• Is it possible to get the names and contact information for three or four survivors and their families who completed the program? I didn't do this and I wish I had. I might have been more aware of problems with the program and acted more quickly to correct them.
• What are the program's weaknesses? What services do you not provide?
• What recourse is there if you question or disagree with the quality or necessity of services being provided?

The Role of the Family
• What role do family and friends play in the program?
• Is the family welcome to regularly attend therapy sessions? If the answer is "No," you may want to look elsewhere.
• What is the visitation policy? Family and friends should be allowed to visit at any time.
• Can a family member sleep in the survivor's room?
• Are there regularly scheduled meetings with the family? How frequently? An initial meeting should be held to discuss the patient's impairments and rehab goals. Then, all parties should meet again at the halfway point to discuss the patient's progress. A third meeting should be held to discuss the patient's homecoming and need for additional therapy.
• Is reading material available to educate the family about brain injury?
• If you live far away, how much telephone contact will there be with the patient and the medical staff?
• Also, what housing arrangements can be made for you?

The Rehabilitation Team
• What are the rehab team members' credentials?
• How long has each team member been on staff?
• How frequently do team members meet to discuss a patient's condition?
• Will you have access to all team members?
• How are student therapists used in the program? Jessica frequently had a student speech therapist, who was not monitored closely by a more experienced staff member.

Addressing Behavioral Problems
• How does the program treat behavioral problems?
• Are restraints, safe rooms, secure and/or locked rooms used? In what circumstances? Is the family consulted about the use of them?

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Addressing Cognitive Impairments

• What approaches are used to treat cognitive deficits?
• Is neuropsychological testing used to determine the patient's core cognitive problems?
• If neuropsychological testing is not performed, how are cognitive problems diagnosed?
• How are the results of these tests used?
• Are patients retested at a later date to determine progress?

Daily Living

• What are the rights and responsibilities of the patient?
• Is there therapy on Saturday and Sunday? Jessica had therapy only on Saturday mornings. These sessions, which were led by a junior therapist in a group setting, were a waste of time and precious health care dollars.
• What will your survivor do in the evening and on weekends? Jessica found Sundays unbearably boring, especially near the end of her stay when she was desperate to go home.
• How frequently is the patient bathed?
• How many workers are on the night shift? What are their responsibilities? Jessica dreaded nighttime. She had difficulty sleeping, was not allowed to go to the bathroom by herself, and often found the night staff indifferent to her needs. We later learned that this is common in many facilities.
• Can the program accommodate any special cultural or religious needs?
• How does the program accommodate special diets and personal food preferences?
• Is outside food permitted for your patient? Jessica had little appetite and was shedding pounds. I was able to tempt her a bit with her favorite foods.
• Are conjugal visits allowed?

Discharge Planning

• How long will your survivor be at the facility?
• Who decides when inpatient rehab ends?
• How is this decision made?
• Where will your survivor go after inpatient rehab?
• What role does the survivor and family have in these decisions?
• Does the staff teach the family how to cope with their survivor's impairments when she returns home?
• Does the staff teach the family how to continue rehab at home?
• How is the patient prepared for going home?
• Will therapists visit your home and help you prepare for the special needs of your survivor?
• Will your survivor be allowed home visits before she completes the program? Home visits provide a clearer picture of a patient's functional problems and should be used to identify therapy goals and exercises.

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• Are there follow-up services after discharge? How frequently? We had five follow-up appointments with the doctor who headed Jessica's rehab team.

Paying the Bills

• How much does the program cost?
• How much of this cost will your insurer pay?
• Are there any charges not covered by insurance?
• How much will you pay out-of-pocket?
• How much flexibility is there with your insurer? We were able to obtain extra outpatient therapy sessions by agreeing to leave inpatient rehab a week early. This worked well because both Jessica and I were ready for her to go home.

Garry Prowe is well known in the brain injury community for his research and expertise in how survivors of a brain injury and their families overcome the considerable challenges they face every day. The author, who holds a master's degree in public policy from the University of Michigan, formed a panel of more than 300 survivors, family members, and healthcare professionals. The author's research also is informed by his role as caregiver to his wife, Jessica, who has a severe brain injury.