



Introduction

Hello. Welcome to the TBIRD VI, the sixth edition of the Traumatic Brain Injury (TBI) Resource Directory. The second edition was completed in October, 1993; the third edition was revised in December 1996; the fourth edition was printed in February, 1998, the fifth edition was printed in March 2000, and this marvelous edition is out February 2006.

This book is intended for the use of anyone with TBI, their family and friends, or anyone who works with people with TBI in the general Santa Clara Valley area. Individuals with other disabilities may find this book useful as well. We feel quite proud of the completeness of this reference. But of course, as we have said in the previous TBIRDs, like any directory of community agencies, it will need updating by the time it's published and available for use. But once again, our past experience with the other TBIRDs has shown us that the vast majority of the information remains current and valuable for anyone seeking resources in the area. We are continuing to use a table of contents and an appendix to help you find information quickly. All agencies are indexed in Appendix A.

Besides the rehabilitation professionals who use this book to help find resources for their clients, this book may be used by individuals with brain injuries, family members, and friends looking for help and resources. For this reason, we have added some narration about each chapter topic at the beginning of the chapter. These chapter introductions are intended to acquaint those who are not so familiar with TBI (or with that particular subject) to the chapter's topic as well as to try to explain why people with TBI may benefit from the services in that chapter.

We do not endorse any of the services nor make any guarantees regarding the information or services included in this directory.

The TBIRD VI gives you information on the entire range of TBI services in the Santa Clara Valley area (and beyond). If you have any suggestions for the next TBIRD or potential additions to or deletions from it, please write, fax, Email, or telephone. We hope that future editions of the TBIRD will continue to help everyone who is impacted by or interested in TBI.

The TBIRD is available on-line at <www.tbi-sci.org/tbird>

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I would like to thank my Co-Editors for this edition: Laura Jamison, Ketra Toda, and Naomi McC Carroll. They were responsible for finding many of the new resources you will find in this edition. Additional resources were found by Travis Casper while he was researching the *Resource Options for Back On Track (ROBOT)* resource guide.

I would also like to thank John Hatten, M.R.C., MS.Ed., as the champion of the third and fourth edition of the TBIRD. John is responsible for the chapter narratives that introduce each section. The original editors of the Traumatic Brain Injury Project Resource Directory were Terry Stimpson, M.S., C.R.C., and Helen Pellegrin, Ph.D. They did a remarkable job in that they started essentially with nothing and gathered information on so many agencies, facilities, and information sources.

This book was peer reviewed by Jeffrey Englander, M.D. and Tamara Bushnik, Ph.D. Their input is much appreciated.

This book would not be as complete without the patience and hard work of Sherri Rogers, who verified names, phone numbers, and other information by contacting all of the resources in this book.

Many thanks to those of you who provided updated and accurate information regarding services.

Most of all we acknowledge the people that use the TBIRD to help themselves, loved ones, or clients.

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A. Index of Agencies/Facilities



TBI 101: *The Very Short Version*

Traumatic Brain Injury (TBI) is a very unique event in one's life: it takes away from a person so many of the qualities that make him/her a person, and it leaves intact other qualities in a seemingly haphazard manner. The person with the TBI is left with a mishmash of abilities, memories, and feelings. And to add a further problem, the person with the injury usually *remembers who s/he was before the injury* and what they could do before; they may or may not be able to appreciate these changes. This can lead to depression (see Chapter 18 if you or your family member/client need help with this or consult Chapter 5 if the need is critical). Brain injury can be a tremendously confusing event in one's life. *But progress can be achieved*, even if the progress seems very slow.

Despite the almost infinite possible combinations of effects of TBI, there are two near certainties: *TBI lasts forever* and *the recovery from TBI lasts forever*. These will be explained in the two paragraphs below.

TBI lasts forever. By this we mean that in the overwhelming majority of persons with TBI, they will continue to feel repercussions from the TBI for the rest of their lives. People with Mild Brain Injury, or MBI, may be able to completely recover from the cognitive problems caused by TBI. An MBI is defined as a traumatically induced physiological disruption of brain function, with any period of loss of consciousness, any loss of memory for events immediately before or after the accident, or any alteration in mental state at the time of the accident (e.g., feeling dazed, disoriented, or confused), and where the severity of the injury includes posttraumatic amnesia (PTA) less than 24 hours or loss of consciousness of approximately 30 minutes or less.

The recovery from TBI lasts forever. This is the good news. Contrary to what was said about TBI in the past (and, astonishingly enough, is still said today by many, including some TBI professionals), the recovery process is a lifelong process (see the introduction to Chapter 17). Now that many people are surviving for decades, it is becoming apparent that improvements can be seen throughout one's life.

We will list here two of the many factors that enter into the **recovery equation** (what recovery can be made and how quickly): *determination to improve* and *organization*. The guts to keep trying to improve no matter what anyone says is important to cognitive retraining. So if you/your relative/your loved one is a stubborn person who won't take no for an answer, you/she/he is on the right track. Organization involves figuring compensations to work around or even overcome attention/memory dysfunctions because most TBI memory deficits are really attention problems. A person with TBI often has an adequate memory for past events, but is less able to make new memories: this is usually caused by a relative inability to focus on the fact or event to be remembered enough to put it into memory. People with TBI can have significant problems with the most 'simple' memory tasks; for example, what the person s/he's talking to just said or what their name is. Just like a person who broke a leg needs a crutch to be able to get around, so a person with TBI needs some way to be cued for information. The resources in Chapter 2 can be helpful with this.

TBI 101: *The Very Short Version*

Another avenue for cognitive and emotional improvement is support. This can come from many sources: family, friends, recreational activities or groups (Chapter 19), support groups (Chapter 22), professionals (Chapter 18), prevocational day programs (chapter 6), a case manager (Chapter 3), or disability agencies (Chapter 7). The support groups can be a tremendous resource as they can help the person with TBI see that s/he isn't alone and that some recovery is achievable.



How to use this directory

Finding information

- Start with the Table of Contents.
- See if you can find the topic that you are interested in.
- Look through the chapter to see if there is a resource that can help you.
- If you find one, you may want to attach a post-it tab so that you can find the page later.
- Write down all of the information that you will need to make your phone call:
agency name, telephone number, name of contact person.

You may also look up resources in the Index. You can find them listed by their name, and also by the city they are located in (handy if you have issues with transportation).

If you are unable to find a resource that will help you in this directory, a good first step would be to call your local Independent Living Center (Chapter 14). They will have a good idea of what is available in your area. A second step would be to call or email us (**Rehabilitation Research Center for TBI & SCI**). We have a TBI resource specialist who may be able to help. Call us at 800/352-1956 and leave a message for the office manager.

Preparation for making a phone call

When you are making a phone call be sure to prepare in advance so that you have all of the information in front of you and you have paper to write down the information you receive.

Before you call, it is very important to know what you want. You will be far more successful if you can make a specific request rather than just asking for “help”.

Making the call

Introduce yourself and give a brief description of your situation. Ask about the services that they provide. The most important point is to remember to NOT GIVE UP at the first sign of resistance. Sometimes people either don't understand your request or are not sure how they can help you. Sometimes you may need to explain your request in several different ways. Many of the agencies/individuals listed in this guide work with many individuals, not just those with brain injuries. You may need to describe your issues and/or problems. Sometimes an agency may not be able to help you, but the person you are talking with can make other suggestions. You will also find that some of the services are no longer offered, or the agency is no longer in business.

Documenting the call

You will definitely want to write down:

- Who you talked with.
- Can they help?
- Are you supposed to call back, or do something else to follow-up?
- Did they give you other suggestions?

