

Surviving & Thriving After Brain Injury:

A Handbook of Strategies for Survivors *by* Survivors

This handbook was put together in 2005 by BIRC Alumni – a group of people from all walks of life who have sustained brain injury and have been clients of the Brain Injury Rehabilitation Center (BIRC) in Portland, OR.

It contains strategies that the authors have learned along the course of their recovery from acquired brain injury and have successfully incorporated into the routines of their lives. These techniques have worked for at least one member of the group; they may not work for everybody with brain injury.

Many were learned and/or reinforced during their rehabilitation program at BIRC. Credit belongs to all who were part of this journey, including the spouses, caregivers, and friends of the survivors, as well as all of the medical professionals who have taken part in care and rehabilitation. The products and/or retailers recommended by the authors are their own recommendations and are not necessarily endorsed by the Brain Injury Rehabilitation staff or Progressive Rehabilitation Associates.

Please tell us what you think! How have they worked for you? Please share you own strategies, so they can be considered for a future edition of “Surviving & Thriving After Brain Injury.”

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Example layout for this handbook -

TOPIC AREA NAME

1. Brain Injury Issue

- **Strategy** (that has worked for at least one BIRC Alumni)

Note: “Caregivers” is used throughout this handbook to mean family members, partners, or anybody who spends a lot of time with a survivor of brain injury.

EMOTIONAL

1. Checking In With Reality

- **Trusted Friend** - The survivor should identify a trusted friend (preferably somebody who knew them pre-injury) with whom they can check in regularly to help figure out what is really true about a particular situation.

After brain injury, the world around you seems foggy and unclear, especially in the beginning of recovery. Many things – situations, feelings, truths - that you once knew to be obvious and clear become confusing. It’s like the world is covered in white medical gauze – life around you becomes very hazy.

Your intuition is damaged. You aren’t always sure if you are completely missing something, second-guessing yourself, getting fixated on a minor detail, or some combination of these. You need somebody who can set you straight and also be brutally honest with you as to what is really happening.

Having a “reality checker” is not only important for the survivor, but also clarifies for others what has really changed about a person and what hasn’t. You need somebody who can tell others, for example: “Yeah, even before injury, Sam couldn’t find his way around town” i.e. Sam has always had a bad sense of direction.

2. “The Big Picture”

- **Internal Dialogue** - A common problem with brain injury is to get fixated on a minor detail and not consider larger, more important items. Before making a big decision, take a step back and think about the “big picture” of a particular project or situation.

Set aside a specific time of day where you ask yourself if you are thinking about the important things. Ask yourself whether you are reacting to the important parts of a situation, or your attention has been captured by a fruitless, energy-wasting detail.

If possible, force yourself to put off making difficult and important decisions for 24 hours. Give yourself 24 hours to “cool down.” You may want to write down the decision you would like to make now, then look at it again the next day and see if you still feel the same. Don’t let others force you into making quick decisions.

- **Internal Dialogue While Driving** - When you become panicked while driving in heavy traffic, force yourself to breathe deeply (four counts for an inhale, eight counts for an exhale) and talk to yourself. For at least one BIRC Alumni, telling yourself, "I can do this; just stay calm and focused," and "I'm okay; the drivers around me don't want to be involved in an accident any more than I do," really helps.
- **Internal Dialogue When Frustrated** – When you become frustrated or angry with yourself for being unable to comprehend what someone is saying to you, losing your train of thought, or being unable to properly identify objects, try to step back and remind yourself of the positive.

You could say to yourself, "I am an intelligent human being. My mind merely processes things differently and more slowly than it did before my brain injury." Also remind yourself that, "Attitude is everything" and "Structure, compensatory strategies and organization are my friends." Promise yourself, “I will be more tolerant of myself.”

- **Create a “Roadmap of Me”** – After brain injury, it is extremely common to compare your abilities “before” and “after” and really focus only on those that have been damaged.

Yet the silver lining is that you often have traits, which were previously obscured by your professional abilities. In other words, you focused so much on your work-related qualifications that you never saw the more subtle traits with which you were born. Post-injury, it is those natural abilities by which you will likely define yourself.

You can identify those by writing three columns on a piece of paper. In the first column (on the left), write down all of the strengths and capabilities – both professional and natural abilities – you had pre-injury. In the middle column, write down all of the attributes you have post-injury. Don’t be shy! Ask your family to identify your new strengths. At the very least, you no doubt have an increased sense of empathy. In the third column (on the right), describe the strategies you are now using (or are available to you!) to compensate for the items in the first column that are now impaired reduced or diminished.

This exercise will help you accept the person you are becoming and acknowledge the fact that you continue to be an intelligent and competent person, except that now you need to use strategies and “work-arounds” to accomplish tasks. The challenge now, of course, is to practice the strategies you’ve learned until they become second nature.

- **Use Brain Injury Support Groups** – After brain injury, especially in the beginning, everybody’s perception of the world is horrifying. You need to talk with people who have had an experience like yours. Non-brain-injured friends, family, and clinicians can never understand exactly what it is like.

There are many brain injury support groups all around the state. Go to a few of them to find out which is the most comfortable for you. Look for the ones that focus on positive, optimistic-thinking the majority of the time. Of course, it is important to be able to vent about problems to people who can really understand. But it is not worth your energy to attend those groups where people are constantly complaining (and not exchanging brain injury strategies).

- **Volunteer!** – Never underestimate your ability to help others, either those who have brain injury or another problem. Almost instantly, you gained the ability to sympathize and empathize with others, particularly those who are beginning the terrifying journey after brain injury. Volunteering can give you a sense of purpose which might otherwise be absent in your life. Volunteer work is a good substitute for gainful employment as it gives you a sense of accomplishment and value.

3. Life Before and After Brain Injury

- **Be Careful of the “Golden Glow” Effect** - Another common problem for those with brain injury is to mistakenly believe that they didn’t have faults prior to injury and that *every* problem post-injury is directly due to the brain injury. In other words, it is easy to look back and think that, before injury, you had a “golden glow” or sparkle to you that meant perfection. You didn’t!

It is important to know which problems and faults are new and which have always been there. Making this distinction is important so that your now limited energy can be devoted to addressing the most important problems (for you).

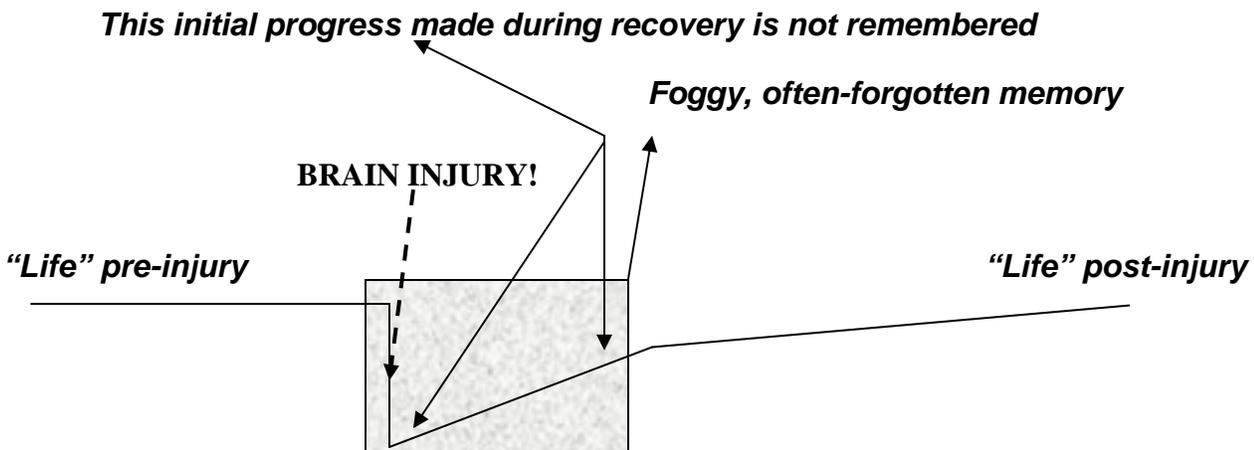
Trying to address *all* problems without prioritization is a recipe for failure. Caregivers, too, need to remember not to attribute all current problems to brain injury; their loved ones had faults in the past. But survivors need to remember that this is a two-way street; things *have* changed. The survivor and their family need to come to agreement as to which problems are the most important to address.

- **Concrete Milestones Are Needed for Recovery Process** - One of the main emotional problems caused by brain injury is the tendency for the brain-injured to compare their life currently with the life they led before brain injury

They don’t think about all progress that they made immediately following the event up till now because of memory loss (or because they were unconscious). There is a lack of concrete milestones that would indicate for them the progress they’ve made since the initial injury.

This lack of insight leaves the brain-injured in a “hole” where they can only remember the person they used to be. They do not see how far they have come in the initial weeks of recovery. The fog of brain injury is made worse by the lack of specific, countable milestones during recovery.

Think of this recovery milestone problem like this:



Caregivers can help the brain-injured “remember” their progress by “filling in” that memory for the brain-injured. They can do this by recalling specific events that occurred in early recovery. This might be done by recounting the initial days in the hospital or by providing concrete examples: handwriting samples that the brain-injured wrote in the first few days post-injury, emails that were written the caregiver to family or friends *about* the brain-injured, pictures, etc. Caregivers and others close to the injured might also write a short letter detailing the initial days/weeks of recovery to share with the brain-injured at a later date.

All of these would strengthen and help rebuild the self-awareness that has been damaged and allow the brain-injured to “own” their situation.

COGNITIVE ISSUES

1. Memory Loss

- **Remote Locator** - Can't find stuff? Try Brookstone Store at Washington Square Mall. They have a “Smart Find Remote Locator,” which can be used for finding keys, PDA, binders, etc. It has a 60-foot range. Cost \$60.00. Phone number for Brookstone is 503-968-6404
- **What Day Is It?** - Can't tolerate X's across the calendar date? Try a small straight pin with a colored head. (like a small hat pin) Just poke it through the square on the correct date of the month on the calendar. The pins are available at a sewing store.

- **Proofread** - After writing anything down on paper, ALWAYS proof read what you've written or suffer later!
- **Hard to Count Change at the Checkout Stand?** - If you can't add up coins in the palm of your hand, set the coins on the counter in piles of the same i.e. nickels, dimes, quarters, pennies. Then pick out the correct amount to give to the store clerk. The clerks don't even blink when you do this.
- **Losing Stuff?** Can't find what you are looking for and you just had it in your hand? Chances are you laid it down without making a mental note. Even when you find it, you can't remember when you put it there. This makes recall nearly impossible. The solution is to just go about your day, but write the object down on a special list (of things to look for) so it doesn't slip off your radar forever. Eventually, you will find it again, but by writing it down so that you look for it later, you won't cause your stress level to rise, which causes precious energy to drain away.

The biggest benefit is that you can accomplish other things without wasting your day on this single distraction. If you are on a project, clean up all items at the end of the job; e.g. put the tools back in the tool box after you are done instead of leaving them on the floor or wherever you were working. Unlike before your injury, you may not remember enough about the task in question so that you find the item.

Finally, don't panic. After you have tried and still can't find it, take your list to caregivers and see if they have any ideas. Do this at the end of the day, or some special time so people don't feel like you've been pestering them all day long. Then they may be happy to help.

- **Losing Your Keys** – For most people, brain injury causes them to be absent-minded. In the course of an outing, one can often misplace your house/car keys. Solve this problem by attaching your keys to your belt or purse using a key ring where keys are tethered to you by a retractable string (like custodians use). At first, it will be odd, but you'll start to like the convenience (especially since you no longer have to track them down).
- **Traffic Safety** - In your plan for the day, if an activity involves crossing streets, make a special note to remind yourself to be careful and look both ways before crossing the street.

- **“Give Us the News!”** - Each day, relate one complete news item from the newspaper or a magazine to a family member from memory.

Make them patiently listen and then ask them to read over the article to check to see if you’ve forgotten the basic facts. Start with the “Who/What/When/Where/Why” of a story and then later after you get good at this, try to remember more subtle details.

It is important that they devote their attention to you – no reading, sighing, or rolling of their eyes! For caregivers, this is a great chance to practice their ability to be patient with a brain-injured person. Being constantly patient with loved one is kind of a pain, but the alternatives are much worse!

- **Log of Driving Directions** – Keep a spiral bound notebook in your car so that you can write down directions to locations you go to frequently.
- **Crossword Puzzle & SUDOKU** – Many survivors use crossword puzzles to sharpen their cognitive abilities. An hour a day doing this really helps. One possibility, especially in the beginning, is to team-up with a care giver. One can begin with a big book of basic puzzles, available in any bookstore. Later you can move on to the puzzles in *The Oregonian*.

A relatively new addition to the *The Oregonian* is SUDOKU (also found on the in the “Living” section of the paper. It is like a crossword puzzle with numbers (digits 0-9), although it does not require math skills.

2. Organization

- **Organizer** – BIRC and most other rehabilitation centers recommend that clients use some tool to organize and manage their daily lives as well as record phone numbers, important dates, etc.

Although awkward at first, one quickly learns to incorporate an organizing tool into each day. It is important to note that these are not temporary measures; they will be a permanent part of your life. Indeed, many non-injured people use them on a daily basis. An organizer allows you to stick to your priorities that you set for yourself each day.

When something new and unexpected comes up, don't let it take you off your priorities – if it isn't urgent, write it down so that it becomes a priority for a *different* day. Remember, by using an organizer to keep track of daily plans, etc., *you can save your brain energy for really important things!*

- **PDA** - Use a Personal Digital Assistant (PDA) like a Palm Pilot. In addition to keeping appointments, phone numbers and “to do” lists, you can set alarms to remind you of appointments or when it's time to move on to another task. The computer text also makes it easier (for you and others) to read your writing later on! Cost is \$65-130
- **Daily Planner** – An alternative is a good ol' vinyl binder with a paper calendar. They come in many styles and brands like Day Runner and Franklin Covey Organizer.
- **Phone Log** – Place a basic spiral notebook near each phone at home and work. Use it to record each call you make and receive [who?/when?/phone number?/ a very short summary of call - perhaps a key phrase that captures the meaning of the call for you]
- **Mail & Papers Piling Up** - Whenever papers come in: bills, receipts, any important things, go ahead and feel dumb in the moment and file them/put them away. Otherwise it will take many, many hours of feeling that dumbness to get them organized.
- **Family Schedules** - Use a dry-erase board in the kitchen to put family members' schedules. Any office supply store carries boards with the outline of a month printed on them.

PHYSICAL ISSUES

1. Vision Trouble

- **Use the Library** - Can't read these days? Call Oregon State Library's Talking Book & Braille Services 1-800-452-0292 or www.oregon.gov/osl/tbabs/index.shtml. The local library may have application forms and will demonstrate the very different tape machine. Application forms must be signed by an MD. You can also just get regular tapes from the library. To begin with, try listening to books you have already read; light reading for entertainment purposes is good. Once you're signed up with this program, they will mail you tapes within three days. Magazines on tape are also available. It's all free.
- **Driveway Patrol** – Those with brain injury often have a decline in their peripheral vision, which means they don't notice when somebody else enters the room (which increases the chance that the brain-injured person will be startled).

If you have this problem, consider getting a “Driveway Patrol” for areas you often frequent like your office hallway, etc. This is a microwave motion detector, which radios a wireless signal to another unit whenever something moves into its field of view. An alarm goes off for as long as there is motion. You can get it at Harbor Freight for \$19.95.

2. Hearing Sensitivity

- **Noise Blocker** – Many people have a heightened sensitivity to noise (like that in busy store) after brain injury that makes it unbearable to be in public places.

One solution is to wear headphones, either just set to your music, or headphones with “noise-cancellation” technology in addition to your music. All the big brands have models with this “noise-cancellation” feature. They appear to range in cost from \$49-200. Search <http://reviews.cnet.com/Headphones> for reviews.

3. Cognitive Fatigue

- Cognitive fatigue is often a serious problem for all kinds of brain injury. Essentially, after brain injury, most of us don't have the neuronal "reserves" that we once did – we get more tired, at a faster rate, after we engage in daily cognitive activities (like reading). It is a fatigue unlike anything most of us have experienced in the past; it is different from physical fatigue (EX: lack of sleep) or emotional fatigue (EX: death of a loved one).

To cope with this overwhelming fatigue, survivors and caregivers might start thinking about daily tasks in terms of the "energy" that they require of a person, instead of thinking about tasks in terms of the time needed to complete them (as we in American society are taught to do).

Both survivors and caregivers might think about this new problem (and explaining it to others) using one of the following two ways:

- **Poker Chips** – One analogy could be poker chips. Normally, people start off with a certain amount of energy "chips" each day - we'll say 20- which they "spend" at a certain rate (that is specific to them). For instance, they might spend 15 during a day and have 5 left for the next day. The next day, they might spend 23 (out of 20 +5 from the previous day) on a particularly taxing subject; then they are exhausted.

People with brain injury are given 15 chips each day and they "spend" them at a much faster rate than their non-injured peers. This means they don't have normal reserves of energy. This fact makes it crucial for folks with brain injury to make a daily list of priorities to insure that they have enough energy to complete important tasks.

- **Computer Chip** – For instance, let's say that a person normally has 100 megabytes (MB) to use on daily cognitive activities. Normally, they can do 4 tasks that each require 25 MB of memory each day before they are "full" (and exhausted). After brain injury, one can only do two tasks each day before becoming "full."

- **Heart-Thumping Exercise** – With brain injury, it is more important than ever before to get regular cardiovascular exercise because it gives your brain oxygen and helps increase your cognitive stamina. Walking, basketball, swimming, kayaking, bicycling – just take your pick. It doesn't matter what it is, as long as you're doing it on a regular basis. Start slowly and gradually increase the intensity – keep a log of your exercise routine in your PDA (like a Palm Pilot) or a journal.
- **Environmental Modification** – To decrease the possibility of overloading your system, take steps to reduce stimuli in your work environment, especially if you're in a cubical, by using headphones (set to soothing music or “white noise”) and installing optimal lighting.
- **Take a Break and Exercise** - Take a break from whatever mental activity you're up to, and do something physical. Don't know what to do and you can't go for a walk without taking a map? Well try a video tape exercise program with the sound off and only one person demonstrating the program. Denise Austin has a tape called "Hit the Spot: Best of Hit the Spot." There are four ten minute separate sections, perfect for that mental break.
- **Overload Reset** - When you're alone and so much comes at your mind that it hurts, some folks put on a headset and listen to really loud music. It “resets” your mind after a short while.
- **Pacing Strategies** – Use these if cognitive endurance is a problem for you. It will be easier if you:
 - **Alternating Physical and Cognitive Activities** – To maintain your general endurance, try to switch back and forth between these kinds of activities. For example, try doing the dishes in between reading two chapters of a book. You could also alternate between a cognitive activity (like balancing the checkbook) and “easy” activities (like emptying a trash can.
 - **Use a Motivator or Vibrating Timer** to remind you when to change activities. These can be purchased at the Hearing, Speech, and Deafness Center - www.HSDCstore.org or 1-888-328-2974.

4. Noise Problems

- **Relaxing Music** - Get a walkman with earphones and listen to different stations and write down the name/artist of what you can hear with ease. Then buy your list off the Internet and copy. In the meantime try Norah Jones "Come Away With Me," and Enya's "Only Time." There is another CD called Deep Peace by Bill Douglas.
- **Church Without Music** - Is church driving you crazy these days? It might be the music and visuals. St. Bedes Episcopal Church in Forest Grove, OR from September through June has an 8AM service that is all spoken. Not a note of music to be heard. If Forest Grove has a church like this, larger cities would also offer it.

5. Nutrition

- With brain injury, it becomes even more crucial than before, to get proper nutrition. Eat regularly, but reduce your sugars since sugar is a depressant. Your recovering brain needs optimal "food." Try to increase your intake of antioxidant foods that spark the growth of brain cells like: blueberries, carrots, cranberries, oranges, broccoli, potatoes, almonds, peanuts, milk, tomatoes, and leafy green vegetables. Below is a nutrition card and a weekly chart to help you plan your diet (and to remember what you've already taken in!).

Nutrition Card
Fruit: 2-4
Veggies: 3-5
Protein: 2-3
Milk: 2-3
Carbs: 6-11

Day	Fruit	Veggies	Protein	Milk	Carbs
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

- **Getting Enough Water?** – Get a 64 oz. plastic size cup like that sold at 7-Eleven. Fill one of those with water and drink all day and you'll know you've gotten your 8 glasses. This costs \$1.49 at 7-Eleven for the 64 oz with soda pop or water.

6. Balance

- **Treadmill** – Everyday, walk on a treadmill at a slow pace while holding on. Start off with your eyes open and walk for three minutes with your eyes closed to see if you can keep your balance.

If you don't have a treadmill, put masking tape on the carpet and try to walk on the line one foot in front of another. Have a family member tell you if you are missing the tape.

FAMILY & PARTNERS

1. Communication

- **Safe Time** - There needs to be a regular time of the day or week where the survivor and caregiver(s) are able to talk about fears and frustration without fear that the discussion will spiral downward into anger and hurt.

For most people with brain injury, the best time of day to do this is first thing in the morning, when they have the most energy. Both parties, especially the survivor, should write down the issues, as they come up during the week, which they wish to raise at the next session. This “safe time” lessens the chances for paranoia and passive-aggressiveness because both the survivor & the caregiver(s) know they'll have a chance to vent at a specific time.

In addition, waiting to raise an issue at a specific time forces the survivor to “take a step back” and reassess an issue to see if it is really a problem of over time. If it still bothers them several hours or days later, then it may be worth discussion (as opposed to immediately giving an angry knee-jerk reaction).

- **Time Outs** - When the survivor and family members start to get angry, one of them should call “Time out!” and walk out of the room. These “time outs” help both parties learn how to deal with anger. Use “time outs” to put physical space between you; don't sit there and try to try to rationalize the situation, especially when the brain-injured person is tired.

- **One Fun Thing Every Day** – Try to make sure that you do one, small fun thing everyday, especially at the beginning of recovery. For example, you could go to a local pet store and look at kittens or puppies (even if you have no intention to buy!). Brain injury is an exhausting journey, so doing something fun with your loved ones each day becomes important. Brain injury will be a lifelong thing, so spending all your time working on it is counterproductive and saps energy
- **Plan Your Reactions** - Before reacting to what somebody says to you, take a step back and consider the “big picture” before you react to a perceived insult or criticism. Don’t waste energy on minor things.

It is crucial in many areas of life – family/work/relationships - to mull over a point in your mind and reevaluate whether it is worth addressing. Or perhaps more importantly, plan how you are going to verbalize it. Use the **S.T.A.R** process (described below). Take a step back and think if you are perceiving things correctly and then plan out your response.

- **Secret Signal** - Come up with a signal so that a survivor’s caregiver can indicate to the survivor that attention should be paid to a particular behavior. Have a hand signal or code word that the caregiver uses to indicate that a specific behavior should be started or stopped.

For example, many people with brain injury slur their words. One cause of this is that injury causes them to “forget” to take a breath when speaking, thereby causing slurring at the end of a sentence, especially when they’re tired. A caregiver can rub his/her stomach to indicate that the survivor should stop talking and take a breath.

2. Helping Caregivers

- **Do Something for Your Family** - People’s friends, family members, and partners always take a hit because of brain injury. Yet recovery, especially in the beginning, can make one so self-centered because all the attention is focused on you. It is easy to forget that your loved ones need attention, too. This could be something like making dinner, flowers, or simply asking, “Are you doing okay?” This is important because it keeps loved ones from being resentful of you. With brain injury, you definitely need the support of your loved ones in the long-run.

Two results are possible: the brain-injured person feels needed, and they will feel like they are actually accomplishing something and making a decision. This is a crucial step as many of us have had every decision made for us since our arrival in the emergency room.

3. Problem Solving

- **S.T.A.R Process** – People who attend BIRC are taught this process to help them work through daily issues and problems they will come across in daily life:
 - Stop before you act;
 - Think about your options/alternatives;
 - Analyze your options for the best solution;
 - Respond.
- **Task Analysis:** When faced with a task/project at home or work, break it down into manageable chunks of information. Take a step back and do the following: identify what materials and resources will be needed, what the steps are to accomplishing the task, and then plan. Always review what you've accomplished to see what further is needed, adjustments that need to be made (materials, resources, plans, etc.).

Try to “step out of yourself” and do a mental self-review: How did I do with the goals I set? How well did I use my strategies? Did I alter my work environment to minimize fatigue, etc?

- **Let the Brain-Injured Make Minor Mistakes -** Initially, caregivers do everything to help out the brain-injured. It is very hard for a caregiver to let go, but doing so gradually is essential because it makes the person with brain injury use their problem-solving skills.

For example, when the family is planning a trip some place, let the brain-injured person plan the route or itinerary. Small victories build self-confidence and it keeps the brain-injured from being too dependent. Making small mistakes and “recovering” from them teaches the brain-injured not to “beat themselves up” for larger mistakes. They can learn to forgive themselves and move on. Learning to acknowledge mistakes and then recover from them is crucial for when a survivor goes back to work.

COMPUTER-BASED STRATEGIES

1. Colored E-Mail Fonts

- **Vary colors of e-mails** - Set e-mail software so that different colors indicate “sent” text and “received” text. The division would help orient the brain-injured person when they read the “history” of a particular e-mail as they prepare a response (so they can see who has written what).
- **E-mail Mentoring** - Clients who are waiting to attend BIRC as well as current clients could be paired with BIRC alumni. The goal would be to have an e-mail-based mentoring relationship, where the alum addresses questions that may come up, especially with regard to daily activities. The advantage is that nobody has to waste energy traveling. E-mail allows both parties to plan (and rewrite, if necessary) their responses.

VOCATIONAL ISSUES

- **Going Back to Work** – You feel physically ready to return to the workplace. You’re cured!

Whoa! Even if you feel perfectly healthy, try to delay going back to work as long as possible because your brain needs a lot of time to recover. Try to use all the sick time that is available to you. If you work in the public sector, you can often ask your colleagues to donate their vacation time so that you can stay home longer. Talk to your Human Resources department. When you are at home, “train” yourself by doing cognitive tasks like reading, following a recipe, or doing a crossword puzzle.

When you do go back, go back part-time at first. Since people with brain injury are most alert in the mornings, work part-time for 2-4 hours in the morning for a few weeks and then lengthen to a full workweek *gradually*.

- **When You Return To A Job, What To Tell Your Current Co-Workers?**

Any suggestions? E-mail them to bircalumni@yahoo.com

**How have you explained brain injury to friends and colleagues?
E-mail your ideas to bircalumni@yahoo.com**

- **Workplace Accommodations When Returning To A Job** – When you return to work, talk to your supervisor about ways to get you back up to speed. Your workplace is required by federal law (the Americans With Disabilities Act of 2000) to make “reasonable accommodations” in your work space.

BIRC alumni have found the following changes in their work environment to be helpful: quieter work space that is away from foot traffic; glare screen on computer monitor (reduces eye fatigue); paper phone logs (where you write down who called and who was called).

When appropriate, perhaps when your supervisor or colleagues asks you how you like to communicate, ALWAYS ask that people e-mail you with information or requests. Not only will you have information that you can process at your own speed, it is already written down for you!

If you start a new job, it may be possible for your employer to make these accommodations for you, but they do not need to know about your brain injury

- **Getting A New Job** – If you go back to work at a new job, you should know the following: you are under no obligation to tell an employer (new or old) about your brain injury or any other information about your health. Your health is your business!

Furthermore, it is illegal under the Americans With Disabilities Act as well as Oregon state law for a potential employer to ask any question about your health. It is also illegal for a work reference to say anything about your health to a potential employer (or anybody else). This does not mean you are hiding anything of which you should be ashamed. After all, you wouldn't disclose a history of cancer or sexually transmitted disease to a new employer would you?

Basically, an employer can ask about your ability to perform the job, but not ask about disability during an interview or application process. However, once you have a job offer, an employer can require a physical exam, so long as everyone performing the same job is required to have an exam.

Also, once you are hired, if you have job performance problems and the employer has reason to know you may have a disability, then the employer is required to begin a conversation with you about whether you may be assisted with reasonable accommodations.

Most people with brain injury have found it best not to tell a new employer anything about their brain injury.

The reasoning is this:

Most people do not understand brain injury. In American society, brain injury is not a health condition where the prognosis is commonly understood. It is not like a broken arm where everybody knows what happens in recovery: you break your arm; you go to the hospital; the doctor sets it in a cast; the cast comes off in 8-12 weeks - simple and predictable

Because of this general ignorance about brain injury (together with the highly variable outcome), people are likely to make up their own minds about a person with a brain injury. If they know you've had a brain injury, they are likely to attribute every mistake you make or idiosyncrasy you have to your brain injury, even if you had a particular issue before brain injury.

Normally, even without injury, when you start a new job, it is natural for your supervisor and co-workers to watch you closely for the first few weeks or months. Don't give them an easy (and perhaps, inaccurate) "reason" for any mistake you might make by telling them about your brain injury.

- **“So to Sum Up What We've Been Discussing...”** – In any job, you will no doubt have daily conversations with your supervisor, colleagues, or customers. At the end of each discussion, try to get them to summarize the conversation for you by saying something like: “As I understand it, I'll do X and you'll do Y...” or “So in summary.....”

Asking somebody to summarize a discussion will allow you to add to the notes you've been taking for yourself since the beginning. This is a very common thing to ask at the end of a discussion and the boss will only think that you're paying extra attention. Nobody needs to know the real reason you've asked.

Are there any other workplace workarounds that people have used?

E-mail them to bircalumni@yahoo.com

What about on-the-job strategies that you have found helpful outside of an office setting?

E-mail them to bircalumni@yahoo.com

POSITIVES?

There is absolutely nothing beneficial about brain injury. However, in your quest to make a new life for yourself post-injury, you might consider the flip-side of all of the negatives about this condition.

- **You're A Survivor!** – The fact that you're still breathing and conscious puts you in a special category. A relatively small number of people survive some kinds of strokes and acquired brain injuries. You have come a long way already, though most people with brain injury can't remember initial days of recovery. If you can't remember, ask your caregivers to recount the first few days after the injury. Then you'll see how much you have recovered.
- **You Know The Worst** – We all come across people who complain about something or worry about some issue that comes up in their lives.

Arguably, you now **know** the worst thing that can happen to a person (besides death). What is more, you and your caregivers have survived it and gotten past the worst. You can now concentrate on making a positive new life!

Thank you for reading the first edition of “Surviving & Thriving After Brain Injury”. Please e-mail any suggestions to improve this handbook or strategies that you've found helpful to bircalumni@yahoo.com.