

Caregiver's Corner

-- prepared by Sask. North Acquired Brain Injury (ABI) Services

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ABI Services...serving individuals with acquired brain injury, their families and their communities.

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Welcome..

Welcome to our first *Caregiver's Corner* newsletter – a **new** publication brought to you by the Sask. North Acquired Brain Injury Services Program. The goal of this newsletter is to provide information, education and support to family members and friends that are caregivers for loved ones who have sustained an acquired brain injury (ABI). The newsletter will be released three times a year, Spring (March), Summer (July) and Fall/Winter (November).



Family reaction to a brain injury

It has often been said that brain injury affects whole families, not just individuals. Many difficult stages have to be passed through from the initial shock of the news of an injury, to eventual acceptance that things may now be very different from how they used to be – for both the individual concerned and the whole family.

Headway: The Brain Injury Association.
www.headway.org/uk

10 Warning Signs of Caregiver Stress:

1. Denial about the injury and its effect on the person who's been diagnosed.
2. Anger at the person with an acquired brain injury or at others because no effective treatments or cures currently exist and people don't understand what's going on.
3. Social withdrawal from friends and activities that once brought pleasure.
4. Anxiety about facing another day and what the future holds.
5. Depression begins to break the spirit and affects the ability to cope.
6. Exhaustion makes it nearly impossible to complete necessary daily tasks.
7. Sleeplessness caused by a never-ending list of concerns.
8. Irritability leads to moodiness and triggers negative responses and reactions.
9. Lack of concentration makes it difficult to perform familiar tasks.
10. Health problems begin to take their toll, both mentally and physically.

Adapted from Brain Injury Coping Skills: A support and education program for adults with brain injury and their caregivers. Backhaus, Samantha et al.2012

The Greatest Challenges Faced by Families after Brain Injury and How to Overcome Them:

People set goals when they do not like their current situation and want to make changes. After injury, survivors and their families face many difficult situations, changes, and problems. They often become frustrated because they cannot do the things they used to be able to do. Setting reasonable goals is key for overcoming problems or challenges. Reasonable goals are those which a person can be expected to achieve given his or her current situation. They are practical, specific, reachable, and flexible ways to make your life better. Following is a list of suggestions to help you set reasonable goals:

- 1. **Look ahead of you not behind you** - making comparisons to the way things used to be is common after injury, but these comparisons can have negative effects. Survivors and their family members may become sad, overwhelmed, worried, scared, or angry when they focus on the differences between how they are now and how they were before. Looking ahead can help you feel better because you can make changes to the future not the past.
- 2. **Set goals considering your recent progress** - Setting goals based on how things were going before the injury can lead

to frustration for everyone. Instead, take a look at how things are now, and plan a small step forward from how things are today. Taking one small step at a time will provide more chances for success.

- 3. **Remember that most people set their goals too high** - When people set their goals too high, they may be disappointed if they can't achieve them. They may judge themselves harshly or expect too much too soon. Setting reasonable goals that are reachable increases the chances that you'll get what you want.
- 4. **Take small steps** - If you have a large goal you want to accomplish, break it down into small steps that you can accomplish. Work one step at a time, and eventually, you'll come closer to your large goal.
- 5. **Whose goals is it anyway?** - People often feel pressured to meet someone else's goals. Figure out if the goal is what you want or what other people want for you. Balance what you want and what others expect from you.
- 6. **Some goals take the help of lots of people** - Some goals are too big for one person to handle on their own. You're only human, not superhuman. Recognize your limitations and when you need help reaching your goals, ask for help.

- 7. **Build on your strengths** - After injury, people often focus only on their limitations. Don't lose sight of the good things you have to offer. Learn to recognize what you do best, then use those strengths to help you accomplish your goals.
- 8. **Congratulate yourself!** - People tend to be hard on themselves and don't give themselves credit for successes. Reward yourself when you take steps forward, even if they are small.
- 9. **Keep in mind that no one is perfect** - People often become frustrated with themselves and beat themselves up if they don't achieve their goals. No one is perfect, and no one can reach all of their goals all the time. You may find the goal you set was too high and unreachable. If you don't reach a goal, re-evaluate your progress and try to decide if the goal was actually reasonable for you.



Kreutzer, Jeffrey. "The Greatest Challenges Faced by Families after Brain Injury and How to Overcome Them." *The National Resource Center for Traumatic Brain Injury, Virginia Commonwealth Model Systems of Care.* www.brainline.org

Taking Care of Yourself: Whose Care Comes First?

Care giving requires you to take on new roles. You will need to learn new skills to help your survivor. Keep in mind that all these things are happening at the same time you and your family are coming to terms with the impact that acquired brain injury had on your loved one/family member. You want to help out the best you can and this may leave you feeling drained, both physically and emotionally. You may even be tempted to put your own needs on hold, however this is not the solution. This is because you then won't be able to give the best care or cope with your new tasks.

How can I stay emotionally and physically healthy?

You may move through a series of stages as you come to terms with the changes in your loved one/family member. In the first few months, for example, you might feel happy that they are alive and hopeful that he or she will recover quickly. As time goes on, progress may slow down and you may start feeling anxious or scared. Sometimes you might think that a faster recovery would happen if only he or she would work harder at it. As recovery progresses you may find yourself feeling discouraged and depressed or even guilty....you just don't know how to help your family member/loved one get better.

It is important to realize that you may not go through these stages exactly like this. Knowing what many caregivers and family members go through as they adjust to life after Acquired Brain Injury may help you know that your reactions are “*normal*”.

Although your reactions are “*normal*”, there can be harmful effects if you focus all of your attention on your family member/loved one.

- You may experience **caregiver burnout**.
- You may feel listless, isolated or bottled up. Those who are burned out may try to use alcohol to cope. You may have poor hygiene or have emotional outbursts. These are signs of burnout and compassion fatigue. **Compassion fatigue** is an outcome of chronic, unrelieved stress.

If you do find yourself experiencing *caregiver burnout* or *compassion fatigue* here is a list of what you can do:

- Find a friend or family member to talk to about your feelings or join a support group with other families affected with Acquired Brain Injury. Talking with someone can relieve stress and reduce anxiety because

you will learn you are not alone.

- If stress, sadness or anxiety begins to feel out of control, seek professional help from a counselor, therapist, social worker, etc.
- Take help when it is offered.
- Reward yourself!!
- Deep breathing and other relaxation methods; meditation.
- Exercise, eat a healthy diet and get regular sleep.
- Focus on positive relationship in your life – family, friends, etc.
- Keep a journal to explore your feelings. Give yourself a *break*, by asking for help in caregiving.
- Know your limits in caregiving. It is okay to seek help from others.

Traumatic Brain Injury: A Guide for Caregivers of Members and Veterans.
www.traumaticbraininjuryatoz.org

My Adult Child has an ABI

Acquired Brain Injury (ABI) can be a devastating experience for the parents of an injured adult child. It can bring about many changes, and at a time when the parents at a stage of planning for their own future. It can seem that life and those plans can disappear in an instant when their adult son/daughter sustain the injury.

In coming to terms with the sustained injury, parents and all family members may experience many emotions. These could include:

- Shock and denial ---at the severity of the injury and the consequences it can cause.
- Anger and frustration --- at the circumstances and how it can impact life and your child's life.
- Loss --- change to plans, financial losses, and grieving the loss of the future you may have anticipated for yourself and your children.
- Resentment and guilt --- resenting the changes, feeling that you could have "done something better", feeling guilty, angry and frustrated.
- Loneliness and isolation - -- withdrawal from your peer and social groups as life now has different priorities and direction.

- Lose of interest in activities that you once used to enjoy.
- Mourning/chronic sorrow --- grieving processes rarely end, as a loved one remains in your life, but often as an altered person. It is common to mourn the personality and characteristics that have been lost while learning to relate to a different person.

Relationship and Role Changes:

Depending on the severity of the injury relationships can change in a number of different ways:

- ABI can place a strain on many relationships and marriages.
- Tensions between parents themselves can manifest. Different attitudes and expectations and different ways of coping can aggravate this.
- Becoming a "caregiver" -- it is possible that the injured adult may move back home. This can be especially difficult if the ABI has resulted in challenging behavioral problems.
- Help with grandchildren may be needed when one parent has an ABI and the other is employed full-time.
- Relationships with friends and extended family members may also change. *Continued on pg.5...*



Acquired Brain Injury.....

AFFECTS each family differently.

Can leave behind **LIFELONG** and **ALTERING CHANGES** and **CHALLENGES**.

And can place a tremendous amount of **STRESS** and **STRAIN** on families.

Many parents find that roles in the family change especially if parents feel that others do not understand the ABI....

- Parents may have to take on the role of caregiver for their adult son/daughter.
- Grandparents may have to take on a parenting role with their grandchildren.
- Parents may need to help educate and support other family members and friends about brain injury.
- “Hands on” assistance to their loved one. (ie: bathing, feeding, dressing, supervision, etc).
- The effects of loss of income when the injured individual was the primary income earner.



Useful Strategies:

- Becoming involved in the hospitalization and rehabilitation stages.
- Learning as much as possible about brain injury to assist developing realistic expectations.
- Realistically considering the strengths of individual family members.
- Identifying areas where asking for help would be beneficial and then ask for help.
- Talking about concerns with other family members and friends.
- Keeping daily routines as normal as possible.
- Being open to involvement in support groups and counseling.
- Spending quality time with other family members.
- Encouraging the individual with the injury to gain as much independence as possible as it is important to allow them to learn new skills and be as independent as possible. Be guided by the professionals working with them.
- Remember that a brain injury doesn't change everything about a person and some personality traits, behaviors and interests will remain unchanged.
- Developing and maintaining a good network of friends and activities to avoid becoming isolated.
- Being just as aware of the things the person with ABI can do, as you are of the things they have difficulty with.
- Using supports, like regular respite, when needed.
- Take the time to rest, rejuvenate and care for yourself.

ABIOS – Support for Families: “My Adult Child has an ABI. Acquired Brain Injury Outreach Service, The State of Queensland 2011. www.health.qld.gov.au/abios

Sask North Acquired Brain Injury (ABI) Services

Sask North Acquired Brain Injury (ABI) Services is a group of programs managed by the Prince Albert Parkland Health Region that are part of the ABI Partnership Project.

Following an initial intake meeting, a variety of services may be offered including...

Case Management – evaluation of client needs & development of client-driven goals, assistance with coordinating health services, referrals to other health care professionals/community agencies based on current needs, return-to-work or return-to-school planning, assistance accessing adaptive equipment, and general counseling.

Consultation – providing information to other service providers, agencies or persons in regards to specific client needs/care and ABI in general.

Education – client-specific and general ABI education for individuals, families, and service providers; prevention activities for schools/community groups.

Independent Living Services – assistance with finding appropriate housing (private residence, personal care homes, etc.), facilitate recreation and leisure opportunities, assistance with therapeutic home programming and independent living skills.

Our Service Area:

- Prince Albert Parkland Health Region
- Kelsey Trail Health Region
- Keewatin Yatthe Health Region
- Mamawetan Churchill River Health Region
- Athabasca Health Authority

Program Admission Criteria:

▶ Must have a diagnosis of a moderate to severe brain injury (supported by medical records) & be medically stable.

▶ Be free of active substance abuse and/or be currently involved in a treatment program.

▶ Applicants with a primary psychiatric diagnosis must have symptoms well managed.

▶ Priority will be given to applicants whose brain injury occurred within the past three (3) years.

Community agencies, caregivers, employers, families and schools who require resources may also access services.

How to Access Services:

We accept self-referrals as well as those from health facilities, physicians, any rehabilitation program or

professional support services, schools or community agencies.

Participation in our program is voluntary.

To find out more information on our referral process &/or to receive a referral form, please contact us:

Phone: (306) 765-6630
Toll Free: 1-866-899-9951

“Our mission is to provide individual and family support to people with ABI so that they may live successfully in their communities with improved quality of life.”