



FASD Support Network of Saskatchewan Inc.

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Network News

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A Note to Readers

by Beverly Palibroda

Here we are in the midst of summer. Enjoy each moment because, I suspect for most of you, the warm days fly by very quickly. I noticed school supplies in the store the other day!

Even though summer seems to be a more relaxed time, I know that there are still many individuals, families and professionals out there who might be having a difficult time. Please remember our office is open all summer. You are welcome to call our toll free line for information and support. We would be happy to hear from you and will do what we can to help out; sometimes it is enough to just have someone to talk to.

Toll free support line: 1-866-673-3276

In Saskatoon: 975-0884

Did You Know???

FASD Awareness Across Canada

This cross Canada event will raise awareness about FASD. The participants began in Halifax on May 17th and will end in Victoria on September 9th. The provinces visited are Nova Scotia, New Brunswick, Quebec, Ontario, Manitoba, Saskatchewan, Alberta and British Columbia.

Website: <http://www.faslink.org/Ride01.htm>

FASD Awareness Day

September 9th is FASD Awareness Day. Watch for announcements about community events throughout the province. Are you wondering what FASD Awareness Day is all about?? Visit the FAS World Website at www.fasworld.com/ or the FASDay site at www.fasday.com/. The Network website also has information posted and resources to help you learn more.

Mark these Dates on your Calendar!! Major Events!!

Canada Northwest FASD Partnership Conference

May 21 - 24, 2008

Location: Banff, Alberta, Canada

Website: <http://www.cnfasdpartnership.ca/index.cfm>

Third National Biennial Conference on Adolescents and Adults with FASD

FASD and Mental Health: The Wisdom of Practice

April 10-12th, 2008

Location: Vancouver, BC

Website: <http://www.interprofessional.ubc.ca/Adults.html>

Abstract Submission Deadline: September 15, 2007



FASD and Physical Health and Wellness

Physical health affects all areas of our lives. Because pre-natal alcohol exposure can affect the development of all body systems, individuals with FASD often have a cognitive disability and multiple physical health issues. Individuals may have health problems such as heart abnormalities, chronic ear infections, poor kidney functioning, lowered immunity, or even sleep disorders. Parents, caregivers and mentors play an important role in helping a child or adult with FASD maintain good physical health and wellness.

How does a cognitive disability impact physical health? Because of brain differences individuals typically have a poor ability to recognize or evaluate their own state of health and well being. For example, they may not recognize the signs of a fever or infection and therefore the illness goes untreated. Risk-taking behaviours, impulsivity and the inability to predict outcomes are common for children, youth and adults affected by FASD. These problems result in a much a higher risk for physical injury. These are just two examples of the link between a cognitive disability and physical health.

There is also a connection between our behaviour in our daily lives and our physical health. Imagine a night when you were unable to sleep and then felt too sick to eat in the morning. You might go to work with a pounding headache that lasts for most of the day. Would you be in a great mood and doing your best work? Probably not, but most of us would be able to link the bad day to our physical symptoms. We could explain the problem to our supervisor and then plan what to do so this doesn't happen again. We could follow through with a healthy meal and an early bedtime the next night. The connection between basic health needs and behaviour is often missed by individuals with FASD so unhealthy behaviour patterns continue.

Problems with communication skills also complicate health matters. It is common for a child or adult with FASD to struggle to find the words to tell others what they are feeling. They may use words differently or not be able to accurately describe pain; they may describe pain as an itchy feeling. It can be hard for individuals to identify symptoms or know when the pain started or what helps. Individuals may also be more or less sensitive to pain making the identification of health problems even harder. Because of these difficulties, when an individual with FASD is sick, tired or in pain, they

may act out, shut-down or become angry. When you see difficult and confusing behaviours like this in an individual with FASD, consider basic health needs. It is important to monitor some of the following areas of physical health that individuals with FASD may not be able to self-monitor.

Sleep disorders are a common problem for individuals with FASD. They may have trouble falling asleep, waking up or have problems with nightmares. It may be hard to recognize when it is time to sleep or wake without external cues. Keep in mind your child's sleep habits and consider the link to daytime behaviours.

Another thing to consider is **eating habits**. It may be more difficult for someone with FASD to explain that they are hungry or even to notice hunger. Individuals with FASD may not feel hungry at regular times or may feel hungry more often. It can help to establish regular eating times and to discuss what foods the body needs and why. Some people react differently to certain foods such as sugar, so consider the connection between your child's behaviour and the type of food he or she is eating. Does she become very agitated after eating foods high in sugar? If so, it may be a good idea to restrict refined sugars from her diet.

Is your child **over or under sensitive** to pain or touch? This sensitivity can seriously affect an individual's well-being and ability to function. A child that acts up in a classroom may actually be reacting to pain they are feeling from the texture of their clothes or the buzzing of the lights. Consider cutting the tags out of clothing or using seamless clothing. Talk to your child's teacher about having a quiet space in the school for a sensory break when your child needs to calm down. A young adult with FASD may need a quiet room at their workplace to cope with sensory issues.

Watch carefully for signs of **other physical disabilities** that are diagnosed or undiagnosed. Are there certain body systems that seem to be affected by prenatal alcohol exposure? Could problem behaviours be linked to pain from chronic ear infections or stomach/ bowel problems? Watch for symptoms of discomfort or illness that an individual with FASD may not be able to recognize or communicate.



Helpful Resources

Individuals affected by FASD may need reminders about ways to keep their body healthy and safe. One good way to teach about healthy and safe living is through the use of plain language and visual aids. Individuals with FASD are often visual or concrete learners so pictures and visual aids really help.

- A good resource for teaching about health is the Vocational and Rehabilitation Research Institute website. There are several plain language documents available for use in discussing health issues such as nutrition, sexuality and eyesight. Please visit <http://www.vrri.org/content/view/245/193/> to view the resources.
- More helpful resources can be found at Kozmic Visual Connections by Shelley Kolisnek. Shelley creates visual and plain language resources that teach adults and children with disabilities about healthy routines, hygiene and emotions. Please visit <http://members.shaw.ca/kvcweb/default.htm> or contact Shelley by phone or email at 978-3362 or kozmicvc@shaw.ca.
- **Telephone Hint:** Create a list of health phone numbers for your young adult such as 911, poison control, your family doctor, a walk in clinic, and 3 people to call to ask health questions. Include when it is ok and when it is not ok to call each number. The provincial health line is a good source of information

HealthLine
1-877-800-0002

Health Check-In

Individuals with FASD can sometimes identify health problems but may need support in identifying what the issue is and when the symptoms are bothering them. One helpful strategy is to do a simple verbal check-in with the individual on a regular basis. Ask the question using simple words and choices that they understand:

- Do you feel sleepy or wide awake?
- Is your belly empty or full?
- Are your hands sweaty or dry?
- Do you feel safe or unsafe?
- Do you feel hot or cold?

These questions can help you to gather information and begin to identify what the problem is. Use these choices at good healthy times and at harder less healthy times to establish a routine and to teach about identifying health needs.

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Hints For a Good Night's Sleep

Sleep is an important part of staying healthy. Some things to keep in mind when trying to ensure that your child receives a good night's sleep:



- A bedtime routine. A consistent routine of several “calm-down” activities can create structure and predictability that can help replace the internal cues that tell us when it is time to go to sleep. The routine can include things like bath-time, brushing teeth, reading a story, hugs or quiet music.
- It helps if a child or adult with FASD goes to bed and gets up every day at the same time, even on weekends or holidays. This builds a healthy routine.
- Consider the medication your child may be taking for attention or other difficulties. Are there side effects associated with sleep? Discuss these side effects with your doctor. Maybe there are alternate medications or alternate times when the medication should be taken.
- Try several different ways of waking an individual with FASD. Some people may be fine with an alarm clock, others may do better with physical touch to wake up. Consider things like vibrating alarm clocks and musical alarms.
- You may have to try several different types of bedtime and waking routines to find one that works for a specific individual. Remember, as Diane Malbin says, “Try differently, not harder.”





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Update on Mentoring: Lessons Learned

By Megan Wood

When I first came to my interview for the Mentor-Advocate position in the summer of 2006, I found myself wondering what a mentor really does. Even in my first few weeks of training, I was very unsure about what my days would look like as a mentor. In reading more about FASD, I thought about how I could help adults to create routines, break down daily tasks and go to appointments. I had no idea the real impact that a mentor could have on someone's life and how different mentoring can look for different people. For those of you who may be looking for a mentor, hiring a mentor to work with your family member, or considering becoming a mentor, here are some of the lessons I have learned that every mentor working with people affected by FASD should know.

- Our brains are amazing! They control all behaviours, thoughts and emotions that we have. We truly don't understand how an average brain works, let alone a brain affected by FASD. When frustrated with behaviours, think about what you know about the brain and how FASD changes the way it works.
- Friendships cannot be replaced by mentorship. Everyone needs meaningful relationships. However, this can be one of the most difficult things in life for many people with FASD.



- Mentorship cannot replace the hard work that families and caregivers do either. Keep in touch with family members and listen to their stories – remember that they have lived with this individual and know him or her better than you do.
- Individuals affected by FASD can be very insightful about their strengths, weaknesses, and also in where they need support. Despite this fact, they may not always want to accept the support in every situation. But be persistent! Mentors must be there to remind individuals what their long-term goals are when that individual is stuck in the moment.
- Success has a different meaning to every person. Success really can be felt for one moment.
- No one is independent. We all create natural circles of support around ourselves and we all need reminders and encouragement sometimes. For people with FASD, this support often needs to be created.
- And the most important thing I've learnt so far is that one person really can make a difference in someone's life. That difference won't make hardship go away, but it can create moments of happiness.



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