



FASD Support Network of Saskatchewan Inc.

510 Cynthia Street
Saskatoon, SK S7L 7K7
Toll free number 1-866-673-FASN (3276) 975-0884
fasdnetwork@sasktel.net
www.skfasnetwork.ca

Network News

May 2008, Issue 19

A Note to Readers

by Beverly Palibroda

Warm greetings to the readers of *Network News*. There has been a lot going on throughout the province and across Canada in recent months. See the Did You Know? section below for information about upcoming events and interesting resources. In this issue of *Network News* you will find a fabulous piece of life writing by Margie a parent of an adult with FASD. I hope you appreciate her story and can draw strength from the wisdom she has generously shared with us. Along with this story, I have included an article about the importance of lifelong supports for individuals with FASD.

We are always looking for stories or information to include in *Network News*. If you have a story, photo or article you would like included please contact Beverly at 1-866-673-3276 or in Saskatoon 975-0806 or by E-mail at fasdcommunications@sasktel.net. Just a reminder, past issues of *Network News* are available to download from our website or copies can be sent to you directly by email. Contact the office to request a copy or to be added to our contact list.

Mother's Day is on May 11th and **Father's Day** is on June 15th. The Network would like to wish Moms and Dads all the best on your special day and throughout the entire year. ✨



Did You Know??

Canada Northwest FASD Partnership Conference

Building on our Strengths Stone by Stone International Conference

May 21 - 24, 2008

Location: Banff, Alberta, Canada

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

FACE Research Roundtable

September 9, 2008

Location: Montreal, Quebec

Website: http://www.motherisk.org/FAR/econtent_conferences.jsp

There are many great resources available online. Here is a sample:

Iceberg Newsletter

<http://www.fasiceberg.org/index.htm>

Fetal Alcohol Family Association of Manitoba—Newsletter

http://www.fafam.ca/htm/fafam_main.htm

Public health Agency of Canada—Documents and Fact Sheets

Website: <http://www.publichealth.gc.ca>

<http://www.publichealth.gc.ca>



Letting Go

By Margie

Letting go of our children with FASD as they become adults is like growing old, I think – it's not for cowards or the faint-of-heart!

Our youngest son didn't grow up knowing that he had a disability. He wasn't diagnosed with FAE, as it was called at the time, until 1993 at age 19. He was certain he could do anything he really wanted to do with his life because that's what we had told him for 19 years, ignorant of the disability affecting him. The consequence was that when he moved from our country home to the nearby city, on his own at age 20, he was resistant to asking for, or even seeing the need for help. While he took steps towards the independence that he insisted on, we were just becoming aware of how much help he would need in life; he was going in the opposite direction.

Our son is gentle, funny, artistic, musical, optimistic and generous by nature. He also has difficulty with good judgment, ability to predict outcomes, solving problems and recognizing many health and safety issues. These traits, combined with his desire for intense experiences and lack of discrimination about who to let into his life, meant the next four years of our lives were filled with desperate hours of worrying, helping, interceding and advocating for him. Whatever we could humanly do to try to keep him safe and learn to handle life on his own, we did. There were times I struggled between the desire to protect him and throttle him at the same moment. And then, one day, he disappeared.

It was about a week later that he called and told us he had met a girl on the Internet and moved to another province to live with her and her mother. Though stressed, we realized we were fortunate that the girl and her mother seemed to be nice people. However, we also knew they were probably ill prepared to deal with the many challenges our son would bring them. For a couple of years our son lived with his girlfriend and her mother, and then with his girlfriend in their own place. But, eventually, he was again living entirely on his own hundreds of miles away from us.

It was hard to suppress the desire to control things from a distance for his safety and well-being, but he seemed happy and content in his new hometown and was still anxious to be independent with no apparent desire to come 'home'. So we decided it was best to keep the lines of communication open and try to stay out of his affairs unless he seemed to be asking us for help or appeared to be in a life-threatening situation.

I struggled then, and I still do occasionally, to come to terms with the fear that we may not recognize if our son is in a dangerous situation. I have learned to balance that with acceptance that he really seems to be content with his life the way it is. I ask myself, "If he is content, shouldn't that be enough for me?" And I wonder if maybe I am the one with the problem.

Whenever I grow fearful for our son, I remind myself that we are doing the best we can for him – he knows he can call us any time, no matter what the joy or difficulty, and we will listen, encourage, pray and help him problem solve if he seems to want that. I would rather try to help the supports build up around him while he is in his 30's than to shelter him into his 50's or 60's and have him face life on his own with loss and abrupt change and us not around to help him. I honestly think he will be all right when we are gone. He now lives on a disability pension. He has experienced enough difficulties with his health and other problems that some minimal support is beginning to build up around him. Though we have some valid concerns regarding his ability to manage safely, we've tried to accept that he seems genuinely content with his life. I know that is good spot for him to be in.

At present, if he calls with a problem we talk about it and make suggestions about whom he might try to talk to. Most often, we can do nothing but suggest, and then wait, and pray that he will be able to do what he needs to do, to solve the problem. Frequently we know nothing of a problem or a period of hospitalization until we hear about it 'after the fact' but he is managing! Yes, it is not the life I had envisioned for him when he joined our family at the age of 5 months. But it is a life that he is content with, so I can be no less than that myself. That is all I want for either of my boys.

Best of all, I have finally found the freedom to see what a strong persistent young man he is. I am really proud of the fact that he is trying so hard to be independent, like his brother. What a survivor he is, in the best sense of the word! He, and many of our children with FASD, face more challenges in a week than some of us will face in a lifetime, and still he keeps going—seldom a complaint—not expecting the world to give him everything.

Now, when someone asks me how he is doing, I can honestly say I am proud of him. I feel that God has helped me see that this son is a special gift to us. He has taught us how to live and love, and even let go. ❁

Life-long Supports

By Beverly Palibroda

We have all likely spoken or heard the phrase—children, youth and adults living with FASD will require lifelong supports. Though this is repeated often, it seems that many individuals, service providers and funding agencies still do not believe this to be true or understand what is actually meant by life-long support. It happens over and over that support is withdrawn at times throughout life, especially when the individual is doing well. In reality, the resources need to stay in place because that is what has created the conditions to allow success for the individual. This need for continued support is particularly true for youth and adults. They are most vulnerable to having support withdrawn. This article explores some ideas about how to include additional support and to maintain a level of support that is best for an individual. I hope that this article helps you to think of some of your own ways to ensure that an individual with FASD is able to get the support they need throughout a lifetime.



CHILDHOOD

If possible, start providing extra support and accommodations early on in life. This is often referred to as early intervention. Learn about strategies that other parents have used to parent their children with FASD. The FASD Support Network of Saskatchewan can give you lots of information about useful strategies and parenting ideas. Try some ideas and find out what works for your child. Try to sort out how your child learns, how she best functions at home or at school, find out what is hard for her and what is easy, what she likes or what she dislikes. Watch for behaviour patterns and be alert to the unique strengths and struggles of your child. Use the information you gain in all areas of your child's life and continue to use the information throughout childhood. Be flexible enough to try out new ideas and to stop using approaches that don't work for your child and your family. Of course, you will need to make changes as your child learns and grows. New issues and needs will arise but try to remember that some approaches and strategies will need to continue for a long time; in fact, some will need to continue for a lifetime.



Because your child will need to accept support for a lifetime, it is important to teach your child to feel good about the help she is getting and to feel good about herself. Create opportunities for your child to do things that she likes and that she is good at. Find ways that she can do things for others so she can contribute and build healthy self-esteem.

ADOLESCENCE

As children enter the teen years, they experience physical and emotional changes. This is a tough time for all parents but can be especially hard for those parenting teens with FASD. Even though you may be getting the message to decrease your support and supervision during the teen years, you will find that it is best to continue to “think younger” and use strategies that you know worked in the past. The approaches that helped during childhood will likely still



work or can be changed to work for a teen. A teen with FASD needs more safety guidelines and structure than teens with an uninjured brain. Try to create a safe environment with some built in opportunities for independence. Problems are less likely to arise this way. Your teen will probably need more guidance with social skills, boundaries and relationships than he did when he was younger because now others expect more of him and relationships get trickier in the teen years. Parents may need to learn about and prepare for increased risk taking behaviours like drug and alcohol use, involvement in negative peer groups, wandering, emotional disruptions and acting out behaviours. Some of the issues faced by parents of teens are very serious and can be emotionally draining. Seek out support and help for you and your family to avoid problems with chronic stress and



fatigue. Continue to help your teen develop relationships, build on strengths, feel good about accepting support and come to understand how FASD influences his daily activities and functioning.

Clear and honest information about FASD is important to help you and your teen understand and accept his disability. Many parents find it helpful to keep learning about FASD by reading, talking with other parents or going to workshops.

Continued on back page...

ADULTHOOD

Carry on with your efforts to help the adult with FASD to understand and accept her unique abilities and disabilities. Help her to accept and seek out the support she needs while giving her space to make some decisions and do some things on her own when she is able. An adult might need guidance in choosing trustworthy family members and friends that she can turn to when needed. Those trustworthy people can continue to modify and use support strategies that worked before. Parents, family members and mentors can help individuals to recognize and understand what support they need, and in which areas of life. Some individuals with FASD will want support and be able to let others know what help is needed; others might resist help or not want to ask for help.



Try to be available because they may want help with very specific things like advocacy or help with a serious issue.

It is critical to continue to build on relationships and connections with family and community

members. For example, without a relationship built on respect and trust an adult will be less willing to seek out or accept help in decision-making or problem solving. Some adults come to understand that the support helps to keep them safe and healthy and that they have a right to accommodations to be successful in life. This is a great outcome but it can be a long journey.

It is wise for parents, caregivers and mentors to remember that we will sometimes need to be flexible in how we support adults with FASD. Life is complex and individuals may be involved in crises or be struggling with addictions or mental health issues. At times, we might need to offer more guidance. At other times when life is more settled and the individual is safe and healthy, she may need and want less direction, but will still need some support. During the calmer more settled times a parent, caregiver or mentor will have more energy to recognize all the things that the individual is doing well and can cheer her on. It feels good for all of us to have someone there to help celebrate our successes. ❁



What would you like to **START**, **STOP** or **CONTINUE**?

It is a good idea to sit down from time to time and reflect on our own actions and interactions with others. As a parent or caregiver of a child, youth or adult living with FASD it might be helpful to sit down and do this activity. Find 3 pieces of paper. On one page write **START**, the next write **STOP** and on the third write **CONTINUE**.



Under the heading **START**—write down all those things that you do want to start doing. This could include new approaches or ideas you have learned. It could be something that you tried in the past and would like to try again. Be creative and try to come up with lots of ideas.



On the **STOP** page—write down the things that just don't seem to work. These ideas might be things that work for others, that's OK. Think about the things that seem to create bigger problems for you such as anger, blame or demanding an explanation.



Now consider what you want to **CONTINUE**—in this list you will include all those approaches that are working well, things that you believe in, or even ideas that just need more time. Write down those little things that improve lives, build on strengths and help to achieve successes.

Good Luck! ❁