

November 2014

# FASD Frontline



## Twitter Recap of the 2014 Alberta FASD Conference

On October 20th & 21st Twitter was buzzing with the hashtag #abFASD

[Ceej @rocknrollgrrl Oct 21](#) "@FASDprevent: Best gift ever received... A day off! #abfasd conversation starters! " Thoughtful notes/txts on bad day

[Patricia Morgan @WoetoWOW Oct 21](#) We all need sleep, good food & supportive connections. Getting it at #abfasd

[Denise Plesuk @plesuk Oct 21](#)

Contribution is a way to promote resiliency – Danna Ormstrup #abfasd

[Drew Dudley @NuanceDrew Oct 21](#)

Thrilled to be at #ABFASD here in Edmonton today! These folks do incredible work. True leaders!

[Kara Stang @canuckdmom Oct 21](#) "Take the time to define what defines you" Love this!! @NuanceDrew #abfasd

[Nicole Pike @npike21 Oct 21](#)

@NuanceDrew "What are the values You want to stand for everyday?" #plantomatter #abfasd

[NAIT NewsWatch @naitnewswatch Oct 21](#)

Fetal Alcohol Spectrum Disorder is the leading cause of preventable birth defects in North America #abfasd <http://ow.ly/i/7iBBb>

[FASDprevention @FASDprevent Oct 21](#)

Wanda Beland - accessing housing through the corrections system #abfasd

[Omar Reyes @strangeordinary Oct 21](#)

"FASD does not define me. FASD defines how I navigate the world."- Erin Reimer #abFASD

[EFAN @EdmontonEFAN Oct 21](#)

Early diagnosis essential for kids with #fasd to succeed. When you can name it you can focus on acceptance, interventions & support. #abfasd

[Patricia Morgan @WoetoWOW Oct 21](#)

Solve FASD? Solve poverty, domestic violence & an addictive culture. Inspired by Peter Choate #abfasd



**EFAN**  
Edmonton and area  
Fetal Alcohol Network

This newsletter contains information regarding resources, services, articles, research and any other materials that might inform and provide support to frontline workers and caregivers. If you wish to share information or to be added to our e-list subscription, please contact [edmontonefan@gmail.com](mailto:edmontonefan@gmail.com)



## Top 10 Most Important Sensory Environment Tips By Lauren S. Henry

1. Be clear about what you want your child's room to inspire. Identify what the goals and challenges they presently have as well as in any and every space in your home.

2. Always be decisive about who will be using the room, if it's going to be shared by more than one person or be utilized for more than one function.

3. What are you and your child listening to? Figure out what you want your child to be able to accomplish in their space and if need be, make a list of what scenarios you can change and what you can't. Then you can slowly begin to deduce what sounds you can change from what sounds you can't. At that point, you can design the natural "sound system" in your space.

\*NOTE: Excuses (fear based or safety based) are not the same as situations that cannot immediately shift or change due to something that is out of our personal control, so pay attention to the difference.

4. Look at all of the lighting in your entire home. Pay close attention to how different each room feels. A general RULE to live by: stay away from all florescent lighting, period.

5. Scent. Whatever fragrance is attractive to you and is in alignment with the function you intend to accomplish is what you should surround yourself with at any given time. It has a much more significant impact than you might think! Candles, incense or natural oils are all acceptable just make sure they're all natural.

6. Plants. Do you have any? OR, do you usually say, "I don't have a green thumb?" Whether you do or you don't, it doesn't matter. What does matter is that you have some, period. Silk, plastic or real (the ladder, most preferred of course) – Plants make a very big difference in the home. They bring the outdoors in and create balance. They also ground us, particularly your kids – (just notice the next time you're in a waiting room or an office that don't have any plants – you will see how unsettling it feels. As an added

benefit, keep in mind that certain plants also act as a natural air purifier as they rely on many of the chemicals in the air as their main source of food.

7. Space. We all need it and rarely feel we have enough. That said, it is very easy to create unnecessary clutter and become accustomed to it. When it comes to your child, don't purchase furniture or use your favorite "hand me down" pieces to furnish the room until you've figured out exactly what he/she needs emotionally, mentally and intellectually (as well as the obvious storage needed.) Be wary of the corners, what it's made of and that you remember that less is more. Keep as much space available as possible to avoid closing off the portions of the room.

8. Pleasing your child. Of course, we all want to make our kiddos happy, ease their anxiety and alleviate their fears. However, just because they inform you they love a particular color, theme, superhero, animal etc... (you get the picture) it does not mean you should make that request the plan for the design in your child's room. Not everything translates to working well on a grand scale. (mainly because the design can actually exacerbate their anxiety.)

9. Containers. A big misconception about storage is that using transparent bins is helpful and saves time. I'm here to tell you, it doesn't do either of those things where your kids are concerned. Rather, it can create visual chaos, over stimulation, anxiety, and frustration.

10. COLOR. The cornerstone to creating a room that is truly supportive of your child's unique needs and begins to transform a space into an "assistive technology." Imagine a room that slowly guides your child into the emotional, mental and intellectual state they need to decompress, self-soothe, concentrate, focus and connect.



## FASD-conscious Holiday Strategies for you and your Family

Holidays are a tough time for our kids. We may place pressure on ourselves to try to make holidays perfect. What matters is family and love and learning to live and appreciate each other for our unique gifts. Our kids do the best they can and if other people (aka, family) can't understand that and you have tried to explain numerous times, just ignore them. Cut yourself and your kids some slack-scale back, stay home and enjoy the moments whenever you can get them.

Realize the world especially during the holiday seasons may assault our children's senses. Below are some possible strategies that might make the holidays a little bit more manageable:

- **Have a go bag (sometimes called a busy bag) for your event with things to occupy child - headset, video game, color books, washable crayon or markers, paper, playdoh, picture books, beloved stuffed toys, favorite music or a craft everyone can do. Bring their pillows and blankets. One child may enjoy popping small bubble wrap bubbles another may feel assaulted by that sound.**
- **Bring a crash pad - a bean bag, body pillow, sleeping bag or pop up tent. You can also use a small folding table and add a sheet for a fort.**
- **Be conscious of sound - Have a supply of earplugs handy. Disorganized noise can be a disaster. If music soothes your young person, use it, but do so judiciously; if music is an irritant, keep it off or to a minimum.**
- The train under the flashing lights on the tree can be like standing in an Amtrak station
- Shopping in the grocery store or mall can feel like an earthquake. Find spots in the mall/store that are quiet to have a retreat - quiet hallways or aisles without decorations.
- Multiple normal talking voices can feel like screams

- **Be aware of touch - If your young person is not good at 'dressing up' be happy they are just wearing clothes to whatever event and let the rest go.**

- Give a soft matching t-shirts or sweatshirts to everyone as gifts, make sure they are sensory friendly to you child and involve your child in the process. This makes a family silly photo easier.
- New pretty clothes scratch, pull, tug and itch - trying online shopping at <http://www.softclothing.net/>
- Test drive the clothes before the event and see if there is going to be trouble brewing.
- Bring additional comfy clothes and shoes to change in later. A set of warm favorite pajamas to go home in or a favorite stuffed toy, blanket or sleeping bag. Consider a hot bath for your child before leaving a family function.
- Model alternatives to hugs and kisses. If you don't want a hug, you could.... Blow a kiss. Give a high five or touch thumbs.
- Use "Happy Feet" to put on shoes - if they are lined up correctly the shoes will smile at each other. If they are not lined up right them will frown and have a sad face.
  - **Have a nose for smell - Holiday scents make bring back memories but also may be overwhelming.**
  - We always brought Peace and Calm essential oil - you can use a scent that the child loves the most for calming - lavender, cedarwood - put it into a zip lock bag to sniff.
  - Swimming nose plugs dull scents and can look fun and silly - bring more than one if you are using them so other kids can join in the fun.
    - **Have your eyes on sights – If the celebration is in a room with fluorescent lights, be aware the room may be very noisy and moving for your young person.**
- A pop up tent can be a fun refuge or building a fort (approved by host)
- Bring some fun sunglasses
- Bright lights and colors can be overwhelming and give anyone a headache.
- Bring a night light

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## **Ensuring the Effectiveness of Interventions: Melatonin and Sleep / Circadian Sleep Rhythm Disorders and Melatonin.**

### **Alternate title: Melatonin and Sleep**

Overview by James E. Jan

Sleep interventions for children with FASD must be individually tailored and may be ineffective when there is a primary sleep disorder. Sleep interventions must also attend to the sleep health of family and caregivers as children's sleep disturbances will affect the family household.

Similar to children with other neurodevelopmental disabilities/disorders, children with FASD commonly have long-standing, severe, sleep difficulties. Unfortunately, the diagnosis and management of these children's sleep disorders have been neglected, and the opportunity of reducing unnecessary suffering been missed. There are many consequences of sleep deprivation (such as cognitive and behaviour problems) that may mask/augment/complicate child's diagnosis and associated health problems. More than that, long term sleep loss may have permanent consequences.

Children with neurodevelopmental disabilities/disorders (NDD/D) such as FASD have high prevalence rates of Circadian Sleep Rhythm Disorders (CSR) as well other sleep problems (such as sleep disordered breathing or restless legs syndrome). CSR are characterized by difficulties waking up and repeated waking up during the night and early morning. There are several reasons for the prevalence of CSR in children with NDD that have to do with environmental influences on the brain and the way the sleep/wake centers create day/night sleep patterns.

Anxiety, excitement, strong physical activity, stimulants, exposure to light at bedtime, can delay pineal melatonin secretion and cause delays in falling asleep. Since the part of the brain that interprets information from the environment also controls pineal melatonin secretion, many children with severe neurodevelopmental disabilities/disorders and cognitive problems may develop delayed melatonin secretion.

In order to ensure that sleep interventions and treatment plans are effective, children (as well as caregivers) need to be getting enough sleep. Melatonin replacement therapy is believed to be a safe and effective way to promote normal sleep, and is often necessary in cases where melatonin secretion is delayed or melatonin deficiency has been diagnosed. We recommend medical supervision before taking Melatonin as other primary sleep disorders (such as sleep disordered breathing or restless legs syndrome) should be ruled out.



# Tips for Employers of Individuals with FASD

1. Learn about FASD.
2. Enable modified work days: shorter days, more breaks, etc.
3. Provide specific job descriptions, guidelines and parameters.
4. Keep instructions simple.
5. Use concrete words. Concrete words have single meaning, and describe what needs to occur.
6. Use visual reminders/text messages/written list of task that need to be completed.
7. Expect the individuals with FASD will have the same good work habits and quality of work as other employees have.
8. Teach individuals with FASD their tasks over and over.
9. Provide supervision of the work that the individual is completing.
10. Provide individuals with honest feedback and information about how to improve their work.
11. If they are successfully completing all of their daily tasks in their current position do not expect that they will be able to move to a new position and perform as well.
12. Look for situations that the individual may have struggles, and work on strategies to reduce the struggles.
13. Keep the individual's job/tasks the same each day. They thrive when their work is consistent.
14. Maintain the same work days and hours as much as possible.
15. Change an individual's environment to encourage success.



# FASD: Changing the Conversation

6th National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder

APRIL 9 to 12, 2014  
Hyatt Regency Hotel | Vancouver, BC

*"Rise above principle  
and do what is right"*

– Walter Heller, American economist



Conference Information Online: [www.interprofessional.ubc.ca](http://www.interprofessional.ubc.ca)



## Upcoming Edmonton Fetal Alcohol Network Society Meetings

### Supports & Service Team Meeting

8:30-9:30am  
DECSA 11515 71st

### Society Meeting

9:30-12:00pm

November 4th, 2014

December 2nd 2014



*Are you part of an  
organization or agency that  
works with individuals  
affected by FASD?*

EFAN is continually looking to expand its membership and to establish linkages with relevant agencies and committees in order to build on the networks and

communities capacity, while offering culturally sensitive services across the lifespan. The Edmonton & Area Fetal Alcohol Network is open to all agencies and community members who have an interest in Fetal Alcohol Spectrum Disorder and its related issues. If you are interested in

learning more about EFAN or becoming a member, please visit the EFAN blog or contact the network.

BLOG:

[www.edmontonfetalalcoholnetwork.org](http://www.edmontonfetalalcoholnetwork.org)

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