

PARENT RETREAT 2017

STRATEGIES

FOR CAREGIVERS FROM CAREGIVERS



Table of Contents

03 General Strategies

04 Meltdowns

06 Ownership

07 Confabulations

08 Cause & Effect

09 Memory Deficits

10 Environment

11 Justice

12 Employment

13 Communication

14 Dysmaturity

Parent Retreat

In 2007, the FASD Network held its first annual workshop for caregivers, Parent Retreat. It was envisioned as a time away from the multiple responsibilities, tasks, and stresses of everyday life. The Network wanted parents and caregivers of individuals with FASD to feel that this was time set aside just for them, and a chance to be with others who might understand their experiences.

For the 10th annual Parent Retreat in 2017, the Network travelled to three Saskatchewan communities to bring caregivers from a variety of locations together to learn new information about the disability and connect with each other. During the sessions in Saskatoon, Moose Jaw and Estevan the Network staff had the caregivers in attendance share their strategies and tips for dealing with some of the common struggles associated with FASD.

The result is this booklet, full of information taken from years of experience and developed by caregivers, the true experts in FASD.

The content in this resource was developed by caregivers for caregivers.
The views and opinions are not a reflection of the Network.

General Strategies

- We laugh lots.
- Be open with people, sharing your experiences and stories can help other families and start conversations about prevention.
- The repetition can get tiring.
- If you find something that works, don't take it away.
- Trust your judgement, you're the expert.
- Education is power.
- Sometimes it's okay to admit that some things about FASD just suck.
- We disclosed to our children and now encourage them to find what humour they can in the disability like saying, "that was an FASD moment, eh mom?"
- We find it helpful to think of behaviours as symptoms and try to look back and see what's going on, what's causing the behaviours.
- We journal so we can look back and see when the behaviours are happening and what the common occurrence has been for each.
- We switched schools - it was hard but it was worth it, in the end we realized that no amount of meetings and fighting was going to get my children the support they needed.

PICK YOUR BATTLES
Don't sweat the small stuff!

- Alvina
Saskatoon Parent Retreat


Strategies for Meltdowns

- They are not pretty.
- Your child will likely forget about the meltdown afterwards, they can move on from them. Even if we can't forget about it, they don't remember so we should try to move on too.
- The colour zones (red, yellow, green) – teach them that each color represents a feeling. They will start to recognize when they are getting into the different zones. It helps individuals understand the feelings and behaviors because they may not experience them the same way that we do. It is a concrete way for them to understand the way that they are feeling or acting.
- Just let them have the meltdown.
- Work with the child to see what works for them. For example, some kids need down time after school and then they can focus better. Find out what is going to work for them and that will help them.
- Be compassionate and attentive to their needs.
- Pick your battles.
- If we can tell in the morning that our child is having a bad day already, we let the teacher know before he gets to class, it helps avoid meltdowns at the school.
- Sometimes all they need is rest or food or some alone time and then those meltdowns won't happen. Let them get rid of some of their energy, as this may help as well.
- We need to be aware of what is going on in their head and what their day was like, we may not understand what they are experiencing but we have to understand that it can affect how they behave.
- Knowing when to push them vs when to let them be – you know your child best so you'll get to know what they need.
- Try to get them to focus on something other than the meltdown, it can distract them from the feelings they are experiencing.
- Try to understand their sensory needs and implement strategies that will help with those needs. Often sensory issues are the main reason behind behaviors.
- Learn their triggers, if possible, so you can see when they start getting escalated and begin any necessary physical interventions like weighted instruments or bear hugs.
- Remember – sometimes kids are just kids and will have meltdowns like every other child.

- The timing of what you do is really important - giving the person an understanding of what it is you're going to be doing and preparing them for the transition such as 10 minute warnings before you go to the store, showing them the list of what you're going to buy, talking to them about how it may be noisy and bright in the store, asking them what they think will help them while shopping.
- Change the activity if they're anxious or don't seem like they're going to be able to cope.
- My kid takes her Ipod everywhere. Playing it low or with one earphone in helps keep her senses on at all times so when we enter a loud environment her senses don't instantly go from 0 to 200.
- After a meltdown when the family seems stressed out, I try to bring everyone back together. I wait until after the meltdown is over then I ask the child to help me make cookies or something, we gather the whole family and eat them together as an opportunity to reconnect and move on from what happened.
- We have several kids in the house so we try to avoid an audience to a meltdown so everyone else doesn't get escalated as well - we ask them to go do another task, play in their room, put the radio on, etc.
- The person going through the meltdown needs to know they are safe so that's an important message to give them but it might be best to not try to stop the meltdown.
- Sometimes it's good just to stay with them during the meltdown and as they calm down, move in closer with a touch or a hug when you can.

Strategies for Ownership

- Label things – stickers with names, color coding with nail polish, etc.
- Keep things out of eyesight - often if they can't see it, they won't take it.
- We need to teach them. Be repetitive.
- There needs to be consequences like returning things after they've taken them.
- When they came back with things they “found,” I try to get them to put it back right where they found it so we can talk about who it might belong to.
- Taking away opportunities is a big thing - the school would help us keep her away from the opportunity with strategies such as putting her desk far away from the cubbies.
- It was important for us that the school did not punish the child for the ownership issues, and let us deal with it.
- When our daughter shoplifted we encouraged her to do ‘community service’ at the store so she learned there were consequences and learned some new work skills.
- I check my kids’ pockets and bags every time we leave a store.
- I actually sewed all my kids’ pockets shut.
- Supervision can help with ownership - it can eventually be learnt but we keep an eye out for it.
- We became wary of the word “gifts.”



A hug or two a day
keeps the blues away

- Loretta
Saskatoon Parent Retreat

Strategies for Confabulation

- Try to understand the difference between confabulation and lying. Remember that their brains work differently. Lying has an intent, confabulation doesn't. Sometimes it's hard to tell the difference.
- If the confabulation doesn't hurt anyone, you can just let them tell you their story.
- Utilize their visual memory. You can prompt their visual memory by asking question (ie: what were you wearing). Sometimes helping them remember their visuals will help them piece together the real story. Visuals can be linked back to the memory/event.
- If you're unsure about a story, become a detective and find out!
- They are just people so they will lie sometimes but it's important to know the difference.
- If we find that she is purposefully lying with intent, then we call her on it, sometimes you'll make a mistake about what's a lie and what's a confabulation but we're only human.
- We just live with it unless there's a safety issue – I think a lot of it is her filling in blanks instead of admitting she doesn't know.
- We learned instead of asking big questions like “how was school?” we get concrete like “What did you learn in math today?”
- I study my kid's facial reactions or body placements - I found that he does certain movements or expressions when he's actually lying.

One day at a time!

Saskatoon Parent Retreat

Strategies for Cause & Effect

- Make them accountable for the decisions that they make. Remind them of the consequences that they had to experience for past decisions.
- The consequences need to be as close as possible to the event or issue, if not, they might not remember and won't understand why they are being penalized.
- Make the consequences concrete and easy to understand.
- Investigate as to why the behaviors are occurring. So that changes can be made and behaviors can be minimized.
- Give them a reason (concrete) as to why something happened. If there is no reason they likely will not understand.
- Make sure they understand the consequence they are receiving or will receive if they do something.
- Be consistent with the consequences.
- I believe our kids need the gift of time to figure this out, they can do it eventually we just can't give up on them.
- It takes a lot of teaching over and over again in all situations.
- We found that constant and instant praise helps to encourage learning what things have positive cause and effects.

Strategies for Memory Deficits

- We use a white board that has the different chores or tasks for each child. That way they can see it and then check off the chore once it has been completed. They can go back to the board as much as they want.
- Use lists, calendars, write everything down.
- USE VISUALS!!!
- Use schedules in all areas of life (school, work, home etc).
- Utilize cell phones.
- Consistent routines help.
- We have visuals they can remove once they complete a task like showering, brushing teeth, breakfast - everyday.
- I use the the “Cozi” app - it’s free and you can sync everyone’s calendars so they get reminders on their phones.
- The school started teaching her early to write everything down in her journal - everything like when to shower, when tests were due so instead of me nagging her I’d ask her to see if there was anything left to do on her calendar that day.
- When I feel frustrated that she can’t remember how to do something that she was able to do yesterday I stop myself and say “Ok, she can’t do this today” and I teach her how like it’s the first time again.
- I put together a photo album (or a flash drive) of the big moments of her childhood so when her memory deficits come up and she can’t remember a trip or something we can look for the pictures in the book.

We are all human beings,
even if someone is ‘different,’
we are ALL DIFFERENT!

- Jennah
Estevan Parent Retreat

Strategies for Environment

- Some individuals don't like visuals, we had to take our pictures and everything off the walls.
- Minimal glass in the house.
- Hide toys at night so they're not overstimulated while trying to fall asleep.
- Extra locks on the doors (that are too high for them to reach) or alarm systems so there's no nocturnal wanderings outside of the house.
- Don't change anything without the individual being aware of it.
- Understand the things in their environment that may set them off and modify what you can.
- Try to understand if they need to take a break from things like family gatherings or supper if it becomes overwhelming.
- It was a lot of trial, error and mindfulness to figure out what fits for them.
- We made a safety place in his closet with a whiteboard.
- Her room is her space, she controls everything, all the sensory stuff – the lights, the noise, everything.
- I went on an audit of his classroom to find out what in the environment might be causing some of his behaviours – for example the loud speakers the teacher spoke through were hurting his ears so he was miserable and not paying attention.
- Gym class was way too much for her so I asked for her to be removed from the class.
- We put bright tape on corners, stairs and cupboards for our child with visual processing issues, it affected her depth perception causing her to bump into these things or trip but the colours helped.
- We put a sound machine or a fish tank in the bedroom, the noise helps them sleep.
- We put away anything that could be used violently, such as cutlery, just due to the impulse control issues we see - instead we have stress balls on the counter.
- Our child rearranges the furniture, the heavy work is a good release for him.
- We go to things early so she can get a feel for the room and get settled before it fills up with people. Before high school we went to the school as many times as she wanted to so she could wander around and get a feel for it.
- We discuss what might happen when we transition to the next thing or a new place and what to do if anything happens and where to go if it's too much or overwhelming.

Strategies for Justice

- Go to the court appearances, etc. Make sure that they have support in place for the process.
- See if you can get professionals involved who understand FASD.
- Stay involved in the process.
- Work with everyone involved.
- We advocated to get them alternative measures.

RESPOND TO THE NEED

Not the behaviour!

- Kim
Moose Jaw Parent Retreat

Strategies for Employment

- It can be beneficial to disclose to an employer so they know what's going on, but only with your child's consent.
- If you are going to disclose to employment you also have to provide the employer with education such as a support worker coming in to explain FASD or some resources.
- Explain their strengths and struggles.
- I tell her when things are part of her condition to not feel stupid or embarrassed - just explain that "I live with short term memory loss and I need help."
- Make visuals to help them remember when they work and what is expected of them at work.
- Give them some responsibility when they are younger so that they are prepared a little more as they age.
- Don't expect too much from them like expecting them to work full time, it may not ever be possible.
- Make sure that the transitions into the work field aren't too fast – Work-Ed programs at school can help with this adjustment.

Strategies for Communication

- Be concrete.
- Make sure that they maintain eye contact with you. Get down on their level if needed.
- Find ways to help them remember (ie: do they need to repeat it, or have it written down).
- Make sure they understand what is said in their own way.
- You can stop and ask if they truly understand what certain words mean.
- Try giving instructions without all the extra babble.
- Try to teach them to self-advocate and speak up when they don't understand something – explain that there is nothing wrong with not understanding things.
- Make sure the words you use are consistent with everyone – mom/dad/teacher/etc.
- The mental health counsellor came up with a strategy for our daughter to write down what she was feeling because it might be easier than telling someone.
- Ask a lot of questions about them to encourage communication.


*The only thing consistent about FASD,
it that it's inconsistent*

- Crystal
Moose Jaw Parent Retreat

Strategies for Dysmaturity

- Understand your child's developmental level.
- Always make sure that your expectations are at your child's developmental level.
- Give them responsibilities that are appropriate to their developmental age, this will help them develop life skills and give them confidence.
- Always remember that dysmaturity is a fact. Treat them how they want to be treated, but make sure that there is supervision.
- Advocate to others when your child needs to be treated their developmental age rather than their chronological age.
- I grieved the things she couldn't do with her peers like getting her license but I grieved and told myself, "that's okay, we'll find what she can do."

Embrace the unique way your
child is blooming - even if it's not
in the garden you imagined



THERE IS HOPE.
THERE IS HELP.

FASD NETWORK OF SASKATCHEWAN

510 Cynthia St
Saskatoon, SK
1-866-673-3276
www.saskfasdnetwork.ca