

Health Professionals Making a Difference:
Fetal Alcohol Spectrum Disorder, Alcohol and
Substance Use in Pregnancy, and Breastfeeding

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The wisdom of parents – parents say:

- Raising a child with FASD is challenging, tiring and emotionally draining
- They experience a lack of professional awareness and support by both health professionals and educationalists
- They have become the information source for the providers rather than the other way round
- They often feel that their parenting ability is challenged & sometimes perceive themselves as “bad parents”

The wisdom of parents – parents say:

- They experience feelings of grief and loss - hopes and dreams they had for their child may not be realised
- They worry about their child's future should they become sick or be unable to provide the on-going support their child needs.
- They sometimes feel lonely and isolated -
- Diagnosis was the catalyst that opened the door to meeting their child's needs

The wisdom of parents – parents say diagnosis:

- Brought relief – provided a reason for their child's difficulties
- Removed the blame from them and their child – alcohol's effect in pregnancy was to blame for their child's behaviour difficulties
- Enabled them to find out more specific information about the disability
- Gave them the knowledge they needed to be stronger advocates for their child

The wisdom of parents – parents say diagnosis:

- Helped them obtain support and services
- Helped them understand their child had brain difference and their child's behaviours were “normal” for them
- Paved the way for trying different parenting approaches and to see their child as one who maybe “can't do” rather than one who ‘won't do’
- Enabled them to change goals and set realistic expectations for their child

The wisdom of parents – parents say:

- There is no cook book approach for parenting a child with FASD
- Each child is unique - what works for one child might not necessarily work for another
- Every environment their child goes into presents new challenges
- Although every child is unique they do have many similarities

The wisdom of parents – FASD similarities - parents say their children:

- Are very loving and don't seem to be misbehaving on purpose
- Have many gifts and talents
- Behave differently & need closer supervision than other children
- Act much younger than their chronological age
- Have sensory problems

The wisdom of parents – FASD similarities - parents say their children:

- Often have sleeping problems
- Are poor eaters and/or fussy with their food
- Are easily overstimulated
- Seem fearless in the face of real danger yet fearful about something insignificant
- Have an explosive temper and/or aggressive behaviours
- Are quiet, shy or withdrawn

The wisdom of parents – FASD similarities - parents say their children:

- Live in the “now”
- Need immediate gratification
- Are very impulsive
- Have trouble changing tasks and learning new tasks
- Don't cope well with change – things outside of normal routine
- Need to be taught very simple routines

The wisdom of parents – FASD similarities - parents say their children:

- Can't cope with more than one or two instructions at a time
- Can learn rules by rote but don't understand the action that goes with the rule
- Often “make up” stories or “re-invent” the truth
- Have trouble understanding the rules of “ownership”
- Talk the talk but don't walk the walk
- Don't understand the consequences of their actions

The wisdom of parents – FASD similarities - parents say their children:

- Are very literal in the way they interpret figures of speech
- Don't understand abstract concepts
- Don't understand the difference between fantasy and reality
- Don't understand “stranger danger”
- Can't differentiate between private and public behaviour

The wisdom of parents – FASD similarities - parents say their children:

- Find school very challenging and can't keep up
- Don't seem to remember the rules and are easily led
- Are suspended because of behaviour issues or alternatively hold it together at school then melt down at home
- Have trouble getting along in a group and "taking turns"
- Have very few friends

The wisdom of parents – parents say their child is the best they can be when:

- There is understanding that their behaviours have their basis in organic brain injury and are not “wilful” or “on purpose”
- Everyone who interacts with the child adjusts their attitudes and expectations
- Everyone maintains a sense of humour
- They are given support to build on their strengths
- The environment is structured, ordered and low stimulus

The wisdom of parents – parents say their child is the best they can be when:

- There is constant supervision
- There is a daily stable routine and consistency - the same thing at same time everyday even during holidays
- There are no surprises
- They are given time to transition between activities

The wisdom of parents – parents say their child is the best they can be when:

- Simple concrete language is used
- They are given one instruction at a time
- Tasks are broken down into small steps
- Role modelling is used to teach new skills or behaviours
- They have visual reminders to help them learn routines and rules
- There is lots of repetition when teaching new skills

The wisdom of parents – parents say their child is the best they can be when:

- The environment is adjusted to make it easier to follow rules
- They are given immediate positive reinforcement for good behaviour
- There is a “chill out” area or cubby where they can go when they feel over whelmed
- They are not exposed to violence (includes TV) or inappropriate role models

The wisdom of parents – parents say their child does best at school when:

- School is flexible and makes allowances for their special needs
- Teachers show compassion and are willing to learn about FASD and work with parents
- When behaviour management policy is founded on principles of positive reinforcement rather than punishment
- There is understanding that “fair” doesn’t necessarily mean “same”
- There is no homework

The wisdom of parents – parents say these behaviour management methods don't work:

- Star charts
- Letting them learn from their mistakes
- Punishments
- Rewards that aren't immediate – or taking away a privilege that isn't immediate
- Nagging or threatening

The wisdom of parents – parents say these behaviour management methods don't work:

- Lengthy explanations
- Abstract rules – be respectful, be appropriate, don't be rude
- Choices between compliance and negative consequences
- Time out – if not immediate and for any longer than a minute
- Smacking

The wisdom of parents – parents say it is easier to cope when:

- They have a the support of family and friends who understand FASD
- They have the support of professionals who believe in and have a sound understanding of FASD
- They have support from other parents of children with FASD

The wisdom of parents – parents say it is easier to cope when:

- They are able to attend conferences about FASD especially workshops that give practical parenting tips and strategies
- Their child is eligible for disability services
- They have regular respite and ‘time for themselves’

The wisdom of parents –parents say to advocate successfully it is helpful to:

- Become knowledgeable about FASD.
- Get to know the systems that your child is being exposed to and the rights of your child, especially in regards to access to services.
- give professionals who will be working with your child an information package about FASD, including specific information about your child's strengths and behaviour triggers

The wisdom of parents –parents say to advocate successfully it is helpful to:

- Encourage professionals to understand that your child needs you to be present at appointments, hearings and the like to assist them in understanding information.
- Keep a file on your child that includes all information related to them - diagnoses, reports, test results, etc. and take with you when you meet with professionals.
- Record the details of all meetings, appointments and phone calls and add this information to your child's file.

The wisdom of parents –parents say to advocate successfully it is helpful to:

- find another parent or support person who understands FASD, to attend appointments and case conferences with you.
- If you are parenting with a partner or spouse go to meetings together as much as possible.
- Remember you know your child best, so keep looking until you find professionals and service providers who know what they are talking about when it comes to FASD and who are willing to back you up.