

EXPLAINING A FASD DIAGNOSIS

FOR CAREGIVERS AND SUPPORTS

WHAT IS FASD?

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenge in their daily living and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges.

RECEIVING A DIAGNOSIS

Receiving a diagnosis of FASD can create several feelings in the caregiver and the individual with FASD. Depending on your child's age, they may feel relief from having an explanation for their behavior, but many may be confused by what the diagnosis means. Health care professionals will explain to the caregiver what the diagnosis means, and how to best help the child. However, explaining the diagnosis to the child can be difficult, and it will take time for them to fully understand. There is no right age to tell your child. It is important to answer questions they may have about why they think and act differently than their peers.

TALKING WITH CHILDREN AND TEENAGERS ABOUT FASD

It is important that your child or teenager understands that they have FASD. Your child needs to know about themselves, who they are and how their brain works. Without this information, there is no way for a child with FASD to understand what is happening for them or why their brain works differently than others. We all have a need to make sense to ourselves. Understanding how FASD affects your child will help them do that.

As a parent, you may be worried about talking with your child or teenager about their FASD.

Maybe you are worried about:

- Making things worse.
- Your child being stigmatized.
- Your child being treated differently by others.
- Them feeling badly about themselves.
- Them being angry about how this happened to them.

Some of this may happen but working through these questions and feelings can lead your child to a better understanding of themselves – and even empower them to face the world with more confidence.

HOW TO TALK WITH MY CHILD ABOUT FASD

It depends on the age of your child. Even young children can benefit from information about their diagnosis if it fits with their age and stage. Prepare yourself in advance by getting information about FASD, the diagnosis and the words you will use to explain it. Use concrete, simple terms and try to keep your explanations short – at least at first. You may want to use visual cues (ex: a picture of the brain) to help your child understand what is happening for them. Try to normalize what is happening for them as much as possible, such as “all of our brains are different – we all have different strengths or learning styles.” Talk about your child’s unique strengths and reinforce their worth and abilities. FASD is only a part of who they are.

Prepare yourself emotionally. Try to have supports in place, for both you and your child, before having your talk. Choose the time and place for this talk when things are quiet, stable and there is enough time. You should follow-up at another time to see what your child understood from the talk and to answer any questions. Make sure their support system, such as family members and teachers, also knows about this talk, so that they can support your child and reinforce your supportive messages.

You may need to help your child or teenager deal with anger about having FASD. No one drinks during pregnancy to harm their child. There are reasons why women drink during pregnancy.

Some mothers:

- Do not know they are pregnant right away.
- Do not realize that drinking will harm their baby.
- Have substance issues with alcohol or other drugs and need help to quit or cut down on their drinking.

Acknowledge your teenager’s feelings of anger, fear, or confusion about having FASD. Help them work through these feelings to come to understanding and acceptance over time.

Once your child or teenager understands their disability, it can open the door to more discussion so that you can work together to find ways to address their challenges. Many children and teenagers say that they feel relieved when they find out that this is a medical condition, rather than feeling like they are “stupid” or “bad.” Over time, your teenager will develop positive coping strategies because of their understanding of FASD and will be better able to advocate for themselves in the community.

Begin talking about FASD as early as possible, and take advantage of teaching moments that come up.

- If your child becomes frustrated, explain that they are having a hard time because of FASD, and that you are there to help them.
- If they ask why they cannot do something, explain that their brain is different than other people’s, but encourage them to keep practicing until they get it.

If the child feels angry about their diagnosis, remind them that everyone deals with challenges, but they also have many unique strengths and talents as well.

- Some days will be better than others.
- You can remind them that they are not the only ones with this disability (sometimes kids think they are the only ones).

Continue the conversation as they age.

- Remember to use simple language when explaining FASD to your child, and use examples to make it easier for them to understand.
- “Your brain works differently, like someone in a wheelchair, their legs work differently”.

- Keep in mind that you will need to repeat yourself several times, in different situations, until your child understands. Focusing on the fact that their brain works differently is important at any age.
- You will need to provide more information and present it differently as your child gets older and can better understand aspects of the disorder.

Re-frame the diagnosis in a positive light by reinforcing their strengths while acknowledging the challenges they may face. For example, if a student may be using doodling as a way to focus their attention, similar to individuals needing fidget toys.

GRIEF AND LOSS

Many parents experience feelings of grief, loss, and guilt along their journey with a child with FASD. These feelings are normal and natural. The feeling of loss for what “could have been” for the child can be overwhelming if it is your only focus. Hopes and goals can be adjusted to your child’s strengths. Building on the possibilities can help to shift the focus from negative to a more positive, productive outlook.

The feeling of guilt for the effects of alcohol on the child can also be difficult for parents. No parent sets out to cause harm to their children. People consume alcohol for many different reasons and to various degrees. Often, mothers are unaware that they are pregnant until several weeks after conception and have, unknowingly, exposed their unborn child to alcohol. Some have substance use issues. Whatever the reasons have been for the exposure, intentional harm was not what the mother had set out to do. It is important to recognize these feelings, seek appropriate support and help to understand your own feelings about this. You need to be well, physically, and emotionally, so you can be the best possible parent for your child.

DISCLOSING

It can be difficult deciding when and how much to disclose about your child’s disability. You have the right to choose who you tell.

Finding the comfort point in speaking about your child’s disability and its effects will take time and practice. You may be concerned about ‘labelling’ your child but, most often, people need to know about the disability to fully understand the individual and their needs.

- When your child becomes old enough, ask for their consent before disclosing their disability to the people in their life, it is of the utmost important that your child feels comfortable with this information being shared.
- When you disclose be sure to do the following:
 - Provide education on FASD. Have a support worker accompany you or bring informational resources.
 - Explain your child’s strengths and struggles/challenges
 - Provide suggestions for strategies or accommodations to help your child succeed.
- Information may not be shared between the professionals in the individual’s life so make sure you are disclosing to as many people as you must so everyone is aware of their needs.

The professionals in your life are not the only people you will disclose your child’s disability to. You will also tell family members, and one day, you will tell your child that he or she lives with FASD. Telling them about their disability can lead to self-acceptance and allow them to understand themselves.

- Think about it from their perspective and use words that are appropriate to their developmental level.
- Using books or storytelling can help them understand that they have FASD.
- Provide basic information about FASD and how it affects people. Be sure to avoid shaming or blaming birth mothers.
- Try to explain their disability by focusing on their strengths.
- Try to find role models or peers who are also impacted with FASD.
- Be prepared to repeat the conversation. Bringing it up multiple times can help him remember and process the information.
- Emphasize that FASD is just a single part of their life. It is a disability they have, not the total of who they are.

FASD & STIGMA

Stigma can have a significant impact on the experiences of individuals and families living with FASD. Stigma is the process of pointing out differences in a group of people and giving negative meanings to such differences. As a result of stigma, society does not have an accurate perception of the lives and experiences of certain individuals, and the attributes and characteristics they possess.

Stigma may result in individuals being blamed for their behaviour and prevent an awareness and understanding of the root of such behaviours. Stigma, in the lives of individuals living with FASD, contributes to ideas such as FASD being uncontrollable, notions of substance use, and misinformation surrounding criminality. Such inaccurate representations of individuals' experiences hide the fact that many individuals living with FASD face structural and social inequalities and are often at risk of victimization themselves.

For individuals living with FASD, such negative feelings and experiences may lessen their ability to seek help and support, may have a negative impact on their self-esteem, add to incorrect beliefs and misinformation, and discourage individuals' confidence in disclosing their disability. Stigma, stereotypes, prejudice, and discrimination can exist personally and structurally in families, communities, and in the policies and practices of health care providers, social supports, and community organizations.

Fortunately, there are many ways to combat stigma. Education and awareness are key. Informed individuals can become advocates to spread positive and correct information about FASD. Each of us can learn the true information about FASD and help educate our family, friends and communities. If we challenge the negative conversations about FASD, we can enhance the lives of individuals and families living with Fetal Alcohol Spectrum Disorder.

ADVOCATING

Because FASD is most often an invisible disability and there is a lack of education within the general public, you will have to advocate for your child and their needs. Educating others about FASD and teaching them to put the person before their disability, is the first step in advocacy. This can include providing resources, involving support workers in meetings, or explaining the specific struggles and strengths that an individual has.

The hard part of advocacy is making your way through complicated systems like the educational, justice and medical systems. Understanding these systems may not come naturally, so to do this, you need to develop a set of advocacy skills.

Focus on being the best advocate you can be for your child. Seek out all the information you can about FASD, and take advantage of the services and professionals in your community who can help educate you on the disability.

- Keep records of the meetings and conversations you have about your child.
- Ask other professionals who work with your child to advocate on their behalf, for example, ask your occupational therapist to advocate in the school.
- Be prepared before meetings. Develop feasible, concrete suggestions for how to help your child succeed.
- Getting your child a diagnosis can really help with accessing supports and services that may be available to them in the education and social service systems.
- Maintain open and constant communication about your child with the professionals in their life. Keep them in the loop about what is going on at home and some of the behaviours that may result from any stress or upheavals in your child's life.
- Try to bring extra support when you can, whether it be a family member, friend, or support person. Having support can help you keep your strength while advocating.
- Be persistent in the face of adversity. Never stop advocating for your child. Make sure that the people who need to know are always reminded of your child's needs.
 - You will have to advocate to countless people in almost every system your child encounters. This can be daunting, exhausting and overwhelming so be aware of burn-out and take time for self-care.
- You are the EXPERT. You know your child and how they are impacted by FASD so never feel embarrassed or frightened to speak-up when you know something is a result of their disability.
- Check out resources that teach advocacy skills. Learning additional skills is always beneficial.
- Learn from the individuals with FASD. Always advocate in a way that supports dignity and respect.
- Try to find schools or programs that have education and experience working with children who live with FASD or disabilities in general, this can help alleviate the stress of always having to advocate for your child.
- Create a case management or individual program plan for your child with all the people who may need to be involved. This allows everyone to be on the same page and to know what direction things are moving in.
- Remember that schools and other systems may have limited resources or are unable to make some accommodations so work with the professionals from these systems to think outside of the box to create new, feasible strategies.
- Teaching self-advocacy to individuals can be a great tool so your child can teach and inform their community about their own needs when you are not there.
- Individuals with FASD can learn their own style of advocating by learning more about their disability and how it affects them.
- Practice advocating where it is safe. See if your support worker can put together a group of parents and professionals to practice with and provide mutual support.

- Some resources are available to help guide the process of self-advocacy, such as booklets that encourage the individuals to describe themselves – what they are good at and what they struggle with.
- You can advocate not only for your child but to achieve large changes as well. Staying informed about issues and connecting with politicians at all levels of government to share your concerns can have a large-scale impact.
- Do not be intimidated about going up the chain-of-command to get results for your child.
- Advocating to professionals can have an impact for not only your child, but for other children with FASD. Every time you explain FASD, and your child’s needs, to a professional you make a difference for the next family as well.

SUPPORT

Within your family:

Family members and close friends can be a huge source of support. You can help them understand your child by doing the following:

- Give them basic information on FASD. Do not bombard them with information. Instead, give a quick summary, say you can talk more about the diagnosis or offer some reading material if they want. You can also say you are trying to learn more about FASD at this time. It might sound like this:

“My child has been diagnosed with FASD. It is a brain-based disorder that sometimes makes it hard for people to think and act in expected ways. It is caused by prenatal exposure to alcohol and the effects last a lifetime. There’s more information in this guide/website, and I’m learning more about it as I go.”

- Be open to share your fears and concerns, as well as theirs. They love your child and you.
- Give them time to absorb the information.
- Tell them what your child needs. You are the best guide for the kind of accommodations and support you and your child need.
- Teach them how to guide your child in the best way and explain that guidance is needed. Lead them by reframing actions (ex: saying “the child can’t”, instead of “the child won’t”) in terms of brain function.

Most importantly, focus on strengths and celebrate their successes.

Within the community:

Being out in the community is not always easy when there are others who do not understand your child’s challenges and struggles. There may be people in school, the grocery store or even your neighborhood who have unkind words and thoughts about your child. Remember that these thoughts belong to someone who doesn’t understand that your child has a different way of thinking and feeling. If you want, you can help them see things differently. However, be sensitive to whether this is appropriate to say when your child is present. You may want to give them more information in the form of a flyer, card, or booklet. Try saying things like:

“My child has FASD.” “S/he has developmental delays.” “S/he has special needs.” “His/her brain is wired differently than yours.”

SOURCES

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