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ABOUT THIS BOOK

This book was written for people with FASD. It is meant to help them understand their disability and how it may affect their lives.

This book also has some helpful tools and examples that you can use in your home. Blank copies of these tools can be downloaded at www.saskfasdnetwork.ca/resources

If you have any questions or concerns about the information in this book. Or if you need support, contact the FASD Network at:

1-866-673-3276 or info@fasdnetwork.ca

WHAT IS FASD?

FASD stands for Fetal Alcohol Spectrum Disorder. When someone drinks alcohol while they are pregnant, the alcohol can change how the baby's brain grows. This can cause a person's brain to work differently. Sometimes things can be more difficult when you live with FASD.

Learning more about FASD can help you understand why some things may be hard for you. It can also help you understand what kind of support you might need to be successful. This book was written by the FASD Network (the Network) to help people with FASD learn more about the disability. This book will explain some common struggles that people with FASD often face as well as challenges you may experience when you don't have the proper supports. While the next few pages will list areas of struggle, it's important to remember that you have a lot of strengths and talents as well.

All Mothers Care about Their Children

Mothers don't drink alcohol to hurt their babies. Sometimes a mom does not know she is pregnant, sometimes she does not know that alcohol is bad for the baby, or sometimes a mom can have an addiction to alcohol. It is important to not drink alcohol while pregnant but we must not shame or blame mothers who have children with FASD. It is helpful to understand that no mother wants to harm her baby on purpose. All women need the support of families, friends, and communities to have healthy, safe pregnancies.

FASD is Common

Most people don't understand how common FASD is. The latest research says that 4% of Canadians have FASD, that's approximately 1,451,600 people in our country. The Network often hears that people with FASD feel alone, sometimes they feel like they're the only ones living with this challenging disability. By looking at how common FASD is, we can see that people with this disability are not alone, it affects a lot of people in our country.

FASD is Lifelong and Invisible

Some people in our lives (including professionals) may not know a lot of information about FASD which can result in myths about the disability. Two important things that people often don't know about FASD is that it is an invisible disability and it is life-long.

An invisible disability means that people can't see it. Some people with FASD may have certain facial features but most people with the disability do not. This means that sometimes people don't believe they have the disability or don't understand how to support them since they can't see the disability. FASD is life-long. That means that it is a permanent disability that will not go away as someone grows older. People with FASD need support throughout their entire life.

PRIMARY DISABILITIES

Primary disabilities are caused by being exposed to alcohol while in the womb. There are four types of primary disabilities: cognitive, behavioural, physical and sensory. Each individual with FASD may experience these differently. In the next few pages we will explain what each of this four disabilities mean along with examples of how someone with FASD may be affected and strategies to help in these areas.

Since FASD affects everyone differently, some people with the disability may struggle with some of these things while others don't. No matter what areas you struggle with it's important to know that with the right support and by using your personal strengths, there are ways to make some of these struggles easier.

Here's a brief explanation of the primary disabilities:

Cognitive Disabilities

This means thinking and mental tasks. Every day people take in, store, and use information. For individuals with FASD some of these mental tasks can be difficult.

Behavioural Disabilities

This means how people behave and act. Our behaviours are controlled by our brains so a brain impacted by FASD may create behaviours that are different than the way other people behave.

Physical Disabilities

This means medical issues and how someone's body developed. When someone is exposed to alcohol while in the womb, the alcohol can harm their entire body not just their brain. Some people with FASD have medical issues because of this harm.

Sensory Disabilities

This means the information our brains receive from our senses (taste, smell, touch, hearing, and sight). For someone people with FASD their senses may be very high or very low. This can affect a lot of different parts of their lives.

The next few pages will focus on struggles that people with FASD often have. As you read about the struggles, remember that every person with FASD has amazing strengths and talents as well.

PROCESSING INFORMATION

One of the cognitive disabilities that's common for people with FASD is having a slower processing speed. This means that you may need more time to take in information, think about it, and then respond. Often people with FASD just need extra time to think about and process information.

For people with FASD this often makes it feel like they are being overloaded with information. This sometimes causes them to shut down or become overwhelmed. For example, Al lives with FASD. One day Al's teacher asks him a question. Al stops to think about what the teacher just said and how he should answer. But since Al is taking a while to answer the question, the teacher thinks he doesn't understand so she asks a different question. While Al is now thinking about the new question, the teacher thinks he still doesn't understand so she asks a third question. Al is now very confused about which question he is supposed to answer, he feels overwhelmed by all the information that was just given to him so Al just says "I don't know," which upsets the teacher.

Unfortunately most people in our lives talk quickly and expect instant answers to their questions. This often doesn't work well for people with FASD due to their struggles with processing information. This can lead to misunderstandings like in the example about Al and his teacher. Diane Malbin explains that people expect a response in 1-second but it may take a person with FASD 10-seconds to think about how they should answer. Sometimes other people may think that you aren't answering the question on purpose, they may even assume that you are ignoring them or don't care. There are strategies that you can use if this is something you struggle with.

- · Sometimes it helps if you explain to others that you live with a disability. Just remember that it's your choice to tell people you live with FASD, if you're uncomfortable you don't have to tell them.
- · If someone asks you a question and you need some time to think about the answer you can say, "I just need to think for a bit please."
- · If someone is talking fast or giving you too much information, you can ask them to slow down and say one thing at a time.
- · If you don't understand what someone is telling you, try asking them to use different words.
- \cdot You can also try asking them to use less words or not give you any information that is not important.
- · If someone is giving you instructions that seem hard to follow, ask if they can give you step-by-step instructions or show you visual instructions.

VISUAL INSTRUCTIONS EXAMPLE

Here is an example of visual instructions that can be used when a task has a lot of steps or feels overwhelming. This example is for washing the dishes, it can be hung on the wall above the sink and used as a reminder each time someone has to do the dishes. Visual instructions can be hung anywhere in the house and made for any type of task.



MEMORY

People with FASD may also struggle with memory issues. For some people with FASD these memory issues mean they can't remember meetings or appointments. For some people it might also mean that they can remember something one day but not the next.

For example, Jo works at a coffee shop. She goes into work on Tuesday and spends all day making coffee. On Wednesday Jo starts her shift and tells her boss she doesn't know how to make the coffee. Her boss finds this very confusing since Jo spent all day yesterday making coffee. Fortunately her boss knows Jo has FASD so he knows she isn't making it up or being lazy, he reteaches her how to make the coffee.

Unfortunately not all people in your life will understand that FASD may affects your memory. Going through life with memory issues can be very frustrating for people with FASD. Here are some ways you can help aid your memory.

- · Using things such as calendars or cellphones to remind yourself about things you need to remember.
- · Some people find it helpful to create several alarms in their phones for appointments or meetings.
- · Create visual reminders for tasks you do a lot. These can be reminders like the steps to get ready in the morning, chore charts, task lists, a how to get ready for work chart, or a bedtime routine list.
- · Ask a support worker, friend, or family member to remind you when something important is happening.
- · If you're having an bad day and can't remember how to do something, don't get upset. Try to find someone who can nicely explain it to you again.
- If other people in your life seem upset with your memory issues, try explaining to them that it is a part of your disability and not something you do on purpose. Remember that you don't have to tell people you have FASD if you don't want to.

REMINDER LIST EXAMPLE

Here are a few examples of reminder lists that can be hung up in your house to help with memory issues.

Read	Ready for work? Don't forget		
	Work Shirt		
	Black Pants		
	Hair up		
	Black work shoes		
	Lunch		
	Bus Pass		
	Cell Phone		
	Name Tag		

Leaving the house? Don't forget		
House Keys		
Bus Pass		
Cell Phone		
Wallet		
Glasses		
Jacket		
Turn off the lights		
Lock the doors		

Nigh	Night-time Routine		
	Pack bag for school		
	Pick clothes for tomorrow		
	Have a snack		
	Take a bath		
	Brush teeth		
	Use toilet		
	Say "Goodnight"		
	Get into bed		

Daily Chore Checklist		
Check mailbox		
Walk dog		
Cook supper		
Wash the dishes		
Sweep floors		
Take shower		
Pack lunch		
Let dog out before bed		

TIME MANAGEMENT

Most people with FASD learn best when things can be seen or touched. Sometimes things like time can be hard for people with FASD to understand because they can't see it. As a result, people with FASD may struggle with time management, meaning they might not be able to understand how much time it will take to do something or they might be late or miss appointments.

For example, Sue has a meeting at 9:00 a.m. She wakes up in the morning and has breakfast. When she's finished breakfast she checks the time, it's 8:45 a.m. Her meeting isn't until 9:00 a.m, so Sue decides to go curl her hair to look nice for the meeting. When she's done the clock says 8:55 a.m, Sue plays on her phone until the clock says 9:00 a.m, then she leaves the house for her meeting. Since Sue struggles to understand time, she doesn't understand that it will take her 20 minutes to get to her meeting. She knows the meeting is at 9:00 am so that's when she goes to the meeting. Because Sue struggles with time management she is late for her meeting.

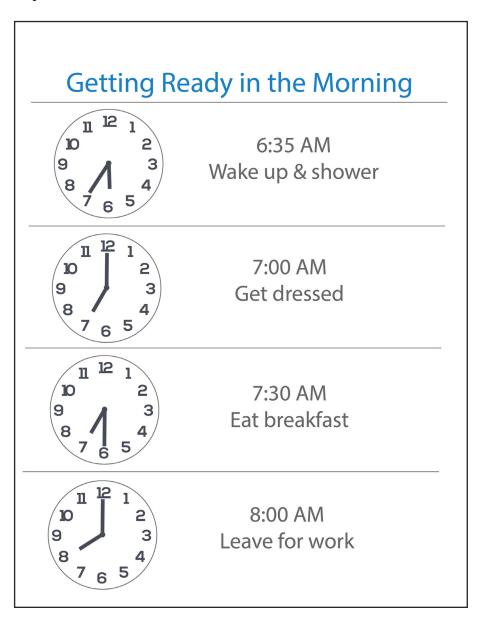
Here is another example of how struggles with time management may affect someone with FASD. Tom works at a hardware store. One day Tom's boss reminds him that today Tom will be doing inventory, which means he will be counting all the items in the storage room. Tom knows this is important and wants to do a good job. Tom starts his shift and goes into the storage room to start counting. At the end of the day Tom's boss comes to check on him. His boss is upset to find out that Tom has been working on this all day but has only counted a few of the items. Tom feels bad that he's upset his boss but Tom struggles with time management so he doesn't feel time pass, meaning two-hours and ten-minutes feel the same to Tom. He wanted to do a good job so he went very slow and careful while he was counting. Tom didn't understand that he took too much time and now his shift was done because for Tom it didn't feel like that much time has passed.

There are a lot of strategies that can help you understand and manage time. Here are just a few:

- · Wear a digital watch everywhere. Digital watches and clocks can be easier to read than the analog clocks.
- · Set timers on your phone or watch to help you know when it's time to move onto a new task.
- · Set alarms to provide reminders.
- You can have reminders hanging up in your house. For example, if you have to leave for work every day at 8:00 a.m. then put a sign next to the clock in your house that says, "8:00 leave for work."
- · Write down all your meetings, appointments, and plans with family/friends. You can write them in a calendar or just put them in your phone. When you write down your plans make sure to put what time you need to be there. You can even write down what time you should leave the house to make it there on time.
- · Try to follow the same schedule every day. If you do the same thing at the same time every day, it will help you understand what time you are supposed to do things.
- · You can hang a schedule up in your house that has each activity next to the time you are supposed to do it.
- · Each night look at your schedule for the next day. This will help you get ready for the next day.
- Sometimes the language that people use to talk about time can be confusing. If the clock says 12:15, some people may say quarter past twelve but other people might say twelve fifteen. This can be confusing so if someone uses language you don't understand ask them to say it in a different way or just write the time down for you.

CLOCK SCHEDULE EXAMPLE

Here is an example of a tool you can make to help with time management. You can make a tool like this and hang it next to the clock in your house. This example includes several things that need to be done at a certain time. This tool can simply be a note next to the clock that says, "leave for work at 8:00 am."



DAILY SCHEDULE EXAMPLE

Creating a daily schedule can help with time management issues. Here's an example of a weekday schedule that could be laminated and carried in your pocket.

6:40 am	Wake up and shower
7:00 am	Get dressed
7:30 am	Eat breakfast
8:00 am	Leave for work
8:30 am	Start work
10:30 am	Take morning break
10:45 am	Go back to work
12:00 pm	Take lunch break
12:30 pm	Go back to work

2:00 pm	Take afternoon break
2:15 pm	Go back to work
4:00 pm	Finish work for the day
4:30 pm	Read or watch tv
5:30 pm	Make supper
6:30 pm	Clean up from supper
7:00 pm	Read or watch tv
9:00 pm	Pack lunch for tomorrow
10:00 pm	Go to bed

ORGANIZING AND PLANNING

It can be hard for people with FASD to organize and plan their day-to-day lives. Another word for organizing and planning is 'executive functioning.' A simple way to understand this is that each day people decide what they want to do that day, then they plan the steps for how they are going to do it, and then they start doing those steps. There are many reasons that someone with FASD may struggle with this. Organizing and planning involves a lot of mental tasks (such as memory, paying attention, and time management) that are hard for people with FASD. When you live with FASD trying to plan and organize tasks can feel very overwhelming.

For example, Kate is hungry but has no food in her fridge. Kate decides this means it's time to go grocery shopping. Kate takes the bus to the grocery store. Once she's in the store she starts walking around looking at the shelves trying to figure out what to buy. Kate begins to feel very overwhelmed so she leaves the store and goes home. When she gets home Kate is still hungry but still doesn't have any food in her fridge. Most people don't think about how many steps it takes to go grocery shopping. Kate struggles with organizing and planning so she didn't know that she should buy food before she runs out, she also didn't know that it helps to plan out what meals she is going to eat and then make a list of what food she needs to buy. Because Kate struggles to plan all the steps of tasks like grocery shopping she sometimes ends up feeling very overwhelmed and upset.

- · Having the same routine every day can help with this. Doing certain things at certain times every day can help you organize your days. Repeating the same tasks is a great way to help your brain learn the steps for how to do something.
- · Ask someone to help you create task lists that break things down into simple steps.
- · When learning a new task write down the steps so you can look back on them next time.
- · You can also create lists or plans for things like chores, to-do lists, or meal plans.
- It can help if you set up your environment for success. Try keeping your house or your room very simple and uncluttered. Having things everywhere can be distracting and cause anxiety. It also makes it harder to find things when you need them.
- · Try labelling where things go and put things away in the exact same spot every time you're done using them.
- · If day-to-day tasks are difficult for you, you can look into getting help. Some people with FASD can get money to pay for a mentor who helps them with things like grocery shopping and doing errands. If you're interested in getting a mentor ask a support worker for help or call the FASD Network at 1-866-673-3276.

MEAL PLAN EXAMPLE

Creating templates that you can fill out can help with being organized and planning for activities. This example is for a meal plan and grocery list. Start by writing down what you will eat each day of the week and then create the grocery list with the food needed to cook each of those meals. The grocery list is divided into the sections of the grocery store to make it easier to find what you need.

MEAL PLAN

GROCERY LIST

SUNDAY				T	
Breakfast	Lunch	Supper	PRODUCE	PANTRY	OTHER
			Lettuce	Peanut Butter	Paper towel
Peanut Butter Toast	Grilled Cheese sandwich	Hamburgers & fries	Onion	Cereal	Toilet paper
	MONDAY	•	Green peppers	Soup	
Breakfast	Lunch	Supper	Apples	Crackers	
			Bananas	Taco shells	
Cereal	Soup & Crackers	Tacos		Granola	
	TUESDAY			Jam	
Breakfast	Lunch	Supper		Spaghetti noodles	
\\\(\)				Spaghetti sauce	
Yogurt & Granola	Ham & cheese sandwich	Sausage & perogies		Salad dressing	
	WEDNESDAY			Rice	
Breakfast	Lunch	Supper		Syrup	
Jam Toast	Pizza Pockets	Cnaghatti		Kraft Dinner	
Jam roast	Pizza Pockets	Spaghetti		Granola bars	
	THURSDAY	<u> </u>			_
Breakfast	Lunch	Supper	BAKERY	FROZEN	MEAT
Cereal	Salad	Chicken & rice	Bread	Hamburgers	Ground beef
Cerear	Jaiau	Chicken a rice	Hamburger buns	French fries	Ham
	FRIDAY			Perogies	Sausage
Breakfast	Lunch	Supper		Pizza pockets	Chicken
 Waffles	Ham & cheese	Pork Chops & salad		Waffles	Pork Chops
	sandwich	. Sitt Griops a saida		Frozen pizza	
SATURDAY		DAIRY			
Breakfast	Lunch	Supper	Cheese slices	Sour cream	
Eggs & toast	Kraft Dinner	Frozen pizza	Milk	Eggs	
		'	Yogurt	Butter	

GENERALIZING

Another cognitive disability that people with FASD may struggle with is difficulty generalizing information. This means that they may understand information in one situation but don't understand that same information in other situations. This means that people with FASD may break rules in new situations because they don't understand that it is still a rule or they may be unable to do a task they learned in a different situation.

For example, a person with FASD knows how to cross the street in front of their house but they run out into traffic when crossing the street at school because they don't understand that the rules and instructions are the same no matter where they are crossing the street.

Another reason people with FASD may struggle with generalizing information is because they are often concrete thinkers. This means that they take everything literally so what they hear is exactly what they do or exactly what they understand.

For example, Todd is playing with his brother Jack and hits him on the leg. Todd's mother tells him "don't hit your brother on the leg!" Todd's mother expects him to understand that this instruction actually means "don't hit your brother at all" but because Todd takes things very literally he thinks she means just Jack's leg so he hits Jack on the arm instead. Todd gets in trouble for doing what his mother just told him not to but Todd couldn't understand that she meant something different than what she said to him.

- · Ask questions. If someone is giving you instructions that you don't understand don't be embarrassed or shy to ask questions. Everyone needs help understanding new things.
- · If you get in trouble for breaking a rule, try to explain what you thought the rule was like Todd thinking it was okay to hit his brother on the arm. This can be a hard thing to do, sometimes other people may be too upset to listen to what you're trying to explain.
- · Creating routines in your life help you understand the situations you will be in each day.
- · If you're in a new situation and don't understand how to do something, ask someone to reteach it to you.

IMPULSE CONTROL

One of the behavioural disabilities that people with FASD may struggle with is impulse control. This means that someone with FASD may get an idea or an urge and immediately act on it without thinking of the consequences. Impulses are thoughts that happen suddenly and can be very hard to resist. For people with impulse control issues they 'live in the moment' so their brain may not be able to stop and think about what might happen as a result of their actions. For some people with FASD issues with impulse control may mean they can't sit still for very long, they have a hard time paying attention, or they always say that first thing they think. Often when people get the impulse to do something it becomes the only thing they can think about. They might even feel growing stress or pressure in their body and only feel relief after they do the impulsive thing they couldn't stop thinking about.

For example, Amy goes to a friend's house for a party. When she walks through the kitchen she sees the cake that all her friends will eat for dessert. When Amy sees the cake she feels the urge to eat some of it. Because Amy has issues with impulse control, her mind can't quit thinking about eating the cake so she eats 3 pieces of cake. She feels much better after, it feels like a relief when her brain stops thinking about eating the cake. Unfortunately, when her friend goes to bring the cake out for dessert, there isn't enough cake left for everyone.

Impulse control issues can lead to people being in dangerous or unsafe situations. Poor impulse control can lead to problems with gambling, shopping, overeating and even problems with drugs and alcohol. There are a few strategies that can help people to try to control their impulses.

- · If there are situations or places where you have been unable to control your impulses, try to avoid them.
- · Impulse control issues can affect your ability to pay attention to things so if you are working on a task try taking breaks for physical exercise like dancing or jumping jacks. This can help you get rid of some of the built up energy in your body so your brain can focus.
- · Fidget items can also help you focus if impulsive thoughts are distracting you. There are a lot of different items you can try, like a stress ball, a fidget spinner, or a tangle.
- · It might help to try to use calming techniques such as taking deep breaths.
- · For some people it can help to avoid unstructured or unplanned time. This means trying to plan out what activities you will do each day.
- It can help having a mentor or a support person go with you to do things. They can be there to help remind you that some impulse actions can have bad consequences.
- · A professional like an occupational therapist or a counsellor may be able to give you other ideas that can help.

FEELING OVERWHELMED

People with FASD may become easily overwhelmed and have "meltdowns" or "outbursts." This is one of the behavioural disabilities caused by FASD. The person does not do it on purpose, their brain is trying to tell them that something is wrong.

Outbursts or meltdowns happen because of a problem. Common reasons can be:

- · The person is struggling with a task
- · They are being given too much information or the information is being given too quickly
- · There has been a change in their schedule or routine
- · They are in a social situation and feel the pressure of having to be on their best behaviour
- They may have sensory issues (these are explained on page 25 & page 26)
- · They might just be having a long, tiring day

It is easy to see why the things listed above may cause stress and anxiety that build up and make someone feel overwhelmed. Meltdowns or outbursts can be your brain's way of telling you and everyone else that it is overwhelmed and needs a break or that something in this situation isn't meeting your needs. It's important to allow yourself to express these feelings and release any pressure building up in your body, but it's also important to find a safe and kind way to express yourself. Here are just a few of the tips you can use to help when you're feeling overwhelmed.

- · If a task is making you feel anxious or overwhelmed try taking a break or asking someone for help.
- Sensory issues can be a big reason for why people with FASD may feel overwhelmed, an occupational therapist can help figure out if you have sensory issues. If you do have sensory issues try telling someone what's bothering you or if you can, leave the area.
- Try to learn the physical signs that an outburst may be coming. After an outburst happens, try to think about how your body started to feel right before the outburst.
- · Learning about the 'Zones of Regulation' often helps people with FASD avoid outbursts.
- · If you feel an outburst coming try to take physical body breaks (do some exercises like jumping jacks) or find a quiet place to go relax.
- · Try using calming techniques like taking deep breaths.
- · Make your own strategies for what works for you, like always having your headphones on with calming music playing at a low volume.
- · It can be good to express these feelings but try to find a safe space first.

ZONES OF REGULATION EXAMPLE

The zones of regulation are used to help people learn how to self-regulate. Each zone represents your emotions or how your body feels. The purpose is to be able to identify which zone you are in and use strategies to help you get back to the green zone. The strategies used for each zone can be customized for each person.

BLUE ZONE	GREEN ZONE	YELLOW ZONE	RED ZONE
I feel: Sad Sick Tired Bored Hurt Upset Not motivated Burnout	I feel:	I feel:	I feel:
STRATEGIES	STRATEGIES	STRATEGIES	STRATEGIES
 Take a break Stretch Think about the happy things in your life Talk to someone about your feelings 	Get work doneHelp others	 Take a break Take deep breaths Go for a walk Listen to music Think of a calm place Use a fidget item 	 Take a break Go to a safe place Talk to somone you trust Self talk Count to ten

SOCIAL SKILLS

Social skills are the skills we use when we spend time with other people. These skills include communicating with each other with the words we say, the way we say them, and the way we use our bodies and faces to communicate as well. As we've explained in the last few pages, people with FASD experience a lot of challenges every day. Trying to overcome these challenges takes a lot of their energy and focus which means they sometimes miss the ways that other people are communicating with them. They may struggle to understand facial expressions, body language, or personal boundaries which can make it difficult for them to make healthy friendships.

As a result, people with FASD may be at risk of making bad or dangerous friendships. On the next page is a chart to help you understand what a good friend is and what a bad friend is. Something important to remember is that some people in your life are 'friendly' but you might not know them well enough to actually be friends. For example you might have the same bus driver every day who is very nice to you, that is called an acquaintance. This is important to remember because it's unsafe to give your personal information to acquaintances or strangers. It takes time to know someone well enough to become friends. The longer you know someone and the more time you spend together helps you learn if that friend can be trusted.

Here are some basic strategies that can help you out with social skills and making friendships or relationships.

- · Work on recognizing body language and facial expression. Some people make cards of different facial expressions that say what emotion each facial expression means.
- · Do things to help understand personal boundaries, like making sure you are always an arm's length away when talking to other people.
- · Join group activities like sports teams, classes, or groups to meet people who have the same interests or hobbies as you. The FASD Network has a monthly peer support meeting in Saskatoon were you can meet other people with FASD.
- · Work with a mentor, support worker, or family member to learn about what makes a friendship good or bad and talk about if any of your friendships may be bad.
- · Ask someone to role play with you. Together the two of you can act out how to meet new people, what different body languages and facial expressions mean, and what to do in different situations.

GOOD FRIEND VS BAD FRIEND EXAMPLE

This list can help you understand how good friendships and relationships are different from bad ones. If you are in a bad relationship or friendship, it's important to remember that you don't have to spend time with them if you don't want to.

Good	Friendshi	inc /Ra	lational	hine
dood	Hichasii	ips/ itc	lations	nips

Makes you feel happy

Supports you/helps you

Understands that mistakes happen

Don't pressure you to do something uncomfortable or dangerous

Accepts you for who you are

You have fun together

You both want to be friends

Bad Friendships/Relationships

Uses anger or violence to get their way

Doesn't respect you

Tries to make you do things you can get into trouble for

Makes you feel hurt, scared, or unsafe

Says mean things about you or makes fun of you

Takes advantage of you (examples are always asking you for money or borrowing things and not returning them)

Here are some ways to help you tell the difference between 'Friends' and 'Acquaintances.' It's important to understand the difference because we don't always know if we can trust acquaintances.

Friends	Acquaintances
You do fun activities together and enjoy spending time together	Someone you might see a lot but don't know much about them and their personal lives
You know a lot about each other	Someone who is doing a job when you see them
You know them well enough to trust them	You don't make plans to go do fun things together
You want to spend time together	Examples: bus drivers, cashiers, janitors
You make plans to spend time together	

PERSEVERATION

Perseveration means someone is stuck thinking about one thing over and over again. Sometimes people with FASD are unable to let go of an idea or topic. Because of this they might not be able to focus on anything else or they might keep talking/asking about the topic they are stuck on. This can happen for many reasons, the person may be excited or they might be nervous or confused.

An example is when Kay's boyfriend says he found a puppy they can adopt. Kay and her boyfriend have to wait a month until the puppy is old enough for them to take home. Kay is very excited to get the puppy so it is all she can think about. She asks her boyfriend every day when they are getting the puppy and it is all she wants to talk about. Kay's boyfriend starts to get annoyed about answering her questions over and over again.

It can be very common for people with FASD to 'get stuck on a thought' when they are supposed to be moving from one task to another. They often seem unable to stop thinking about the old task and can't move on to the new task. This might simply be because they didn't have time to complete the first task or maybe they weren't given any warning that they would be switching tasks. This may seem very sudden and their brain needs more time to move on to a new thought.

Another example is Chad. Chad's teacher gives the class math questions to work on. But before Chad can finish the teacher says it is time for English class. Chad becomes very upset because he was not ready to move on to English and didn't get to finish his math questions. His mind is unable to start thinking about English because it is still focused on finishing the math questions.

Perseveration seems to happen most often when moving from one task to another so here are some ideas to help.

- · When planning your day, give yourself a lot of time to complete everything on your list.
- · Ask for more time and less things to do. For example, if Chad had less math questions to do and more time to work on them he would be able to finish and his brain could move on to a new task.
- You can use your phone or a timer to give yourself warnings that you will have to do a new task soon, like setting an alarm five minutes before it's time to switch and then setting another alarm for when it's time to switch.
- · If you're doing something new or different that will change your usual routine, try to do it in the morning. That way you won't be thinking about it all day.
- Sometimes you can get stuck thinking about a task because you don't want to do the next task, especially if the next task is confusing or hard. It might help if you take a break between the tasks or if you ask someone for help with the new task.

HEALTH ISSUES

We used to believe that FASD only affected a person's brain but now research is being done that explains that FASD affects a person's whole body. There are a few different ways that FASD can affect a person's body.

FASD can affect how a body grows and develops. People with FASD might have differences in how their bodies are formed and how they move. This means they might be clumsy, they might have problems with motor skills or they might be slower to develop physical skills.

FASD can also affect the development of body systems. This means that parts of the body may not function as well as they are supposed to. This can lead to a lot of health problems for people with FASD. Research is still being done to find out what kind of health problems people with FASD often have but so far some of the common problems have been issues with their bones, hearts, kidneys, digestion, hearing, blood circulation, muscles, etc. This is why it can be very important to tell your doctor that you have FASD. Not all doctors know about FASD so you might have to tell the doctor that living with FASD means you might have health issues that other people your age don't usually have.

- · Go to the doctor at least once a year for a physical check-up.
- · If you find a doctor you like, try to always go back to that same doctor.
- · Bring a support person with you to doctor appointments. Most people don't understand FASD so you may need help explaining your health issues.
- · If your health issues make some things hard for you, it's okay to tell other people and ask for help. For example, if you can't hear things very well it's okay to ask people to speak louder and slower.
- · An occupational therapist can help you work on some physical issues like your balance, coordination, and motor skills.

SLEEP

People with FASD may struggle to fall asleep at night and wake up in the morning. There are many reasons why this may be an issue for someone with FASD:

- · They might have irregular sleep patterns.
- · They might be very sensitive to things like touch, sounds, and smells.
- · They might have high levels of energy and struggle to calm down or relax.
- · Their mind might be perseverating or stuck focusing on the activity they were doing before bed.

As a result of these issues falling asleep at night, people with FASD might then have problems waking up in the morning.

If you don't get enough sleep at night it can affect your abilities to function the next day. Without proper sleep you can be tired all day, be unable to pay attention, or even be hyper-active.

Here are some tips to help with falling asleep at night.

- · Create a calming bedtime routine that you follow every night. This can include the same bedtime every night, taking a warm bath before bed, and not watching TV or playing on a phone/computer an hour before bed.
- · Play relaxing music or get a white noise machine for your bedroom.
- · For someone people weighted or heavy blankets can help.
- · Try not to sleep-in every morning. This can make it harder to fall asleep at night.
- · If you can't fall asleep or wake up during the night, have a book beside your bed to read until you fall asleep. This is less stimulating than watching TV.
- · If you struggle with falling asleep at night waking up in the mornings can be difficult as well. Try asking for meetings and appointments in the afternoon instead of the morning so you have time to wake-up and get ready.

OVER-SENSITIVE SENSES

FASD can cause sensory disabilities. Our brain receives information from each sense. This gives us the ability to taste, touch, smell, hear and see. Sensory organs develop in the womb and can be impacted by prenatal exposure to alcohol.

This can lead to people with FASD being over-sensitive to their senses which means they feel things too much. For example, they may be able to feel all the tags on their clothing, they may be able to hear every noise going on around them, or bright lights might hurt their eyes.

When someone has over-sensitive senses they may be so focused on what they taste, feel, smell, hear or see that they can't focus on anything else. They may become overwhelmed by all the information their senses are telling them. People with FASD may shut down or act out as a result of being overwhelmed by their senses.

The best way to deal with sensory issues is to change your environment. Below are some strategies to help:

- · If bright lights bother you try using lamps instead. If you're out in public try wearing sunglasses or a hat.
- · If you are in a loud environment like the grocery store or the mall try wearing headphones or earplugs.
- · You could also try to go at times of the day when there aren't as many people. It tends to be quieter when you go shopping in the morning or early afternoon.
- · If clothing bothers you try removing the tags and washing it several times before you wear it.
- · If you find an item of clothing you like, it's a good idea to buy more than one of the item so you have replacements.
- · If smells bother you try carrying around a scented item that you can hold up to your nose when something smells bad. You could try items like small car air fresheners or bottles of scented oils like lavender.
- · If you start to feel overwhelmed by sensory information try taking a break. If you can, leave that room and take a break for a few minutes.
- If there's something that is really bothering you, try asking politely if it can be changed. For example, if you are in a meeting with bright lights try asking if it is possible to have the lights dimmed. Or if someone is making a noise like tapping their foot against their chair you can nicely explain that the noise is very distracting for you.
- An Occupational Therapist can be very helpful with sensory issues. They can help you figure out which senses may be over-sensitive and can work on ways to help.

UNDER-SENSITIVE SENSES

FASD affects everyone differently. Some people may be over-sensitive to sensory information while others may be undersensitive. Being under-sensitive means that someone may have not feel things as much as other people do. For example, they may not be able to hear very well or they may not be able to taste food unless it's spicy.

As a result some people who are under-sensitive may have sensory-seeking behaviours. This means they may try to find ways to help their senses feel things. This can be behaviours like talking loudly, standing too close when other people are talking, jumping or spinning, playing rough, or touching people and objects.

Being under-sensitive can have dangerous effects on a person's ability to feel pain, hunger and temperature.

- · If someone is under-sensitive to pain they might be seriously hurt but only feel uncomfortable. For example, someone with FASD may be walking around on a broken leg because they don't feel the pain.
- · If someone is under-sensitive to hunger they may not be able to tell when they feel hungry so they'll skip meals which can be very unhealthy.
- · If someone is under-sensitive to temperature they may not be able to tell when something is hot or cold. For example, they may go outside in the winter in shorts if they can't feel the cold and get frost bite. Or they might get into a bath tub that is too hot and end up getting burnt.

- Eat meals at the same time every day. This can help you remember to stay healthy and eat even if you don't feel hungry.
- · If you've had an accident and something on your body looks weird or feels uncomfortable, tell a family member or support person. Explain what happened, they may be able to tell you if you should go see a doctor.
- · Try using heavy blankets like sleeping bags to sleep at night.
- · If you struggle to dress for the weather outside, make a chart that shows you what to wear for each temperature.
- · Use a thermometer for things like bath tub water to make sure it's safe to get in to.
- · Sometimes people who are under-sensitive feel better after someone else gives them a tight squeeze. Try asking someone you trust to give you a tight hug and see how it feels.
- · Fidget toys can be a good way to help you feel senses such as touch and movement. Sometimes playing with a fidget toy helps people concentrate on what's going on around them like in school or at meetings.
- · An Occupational Therapist can also help people who are under-sensitive. Talk to a family member or support worker about finding an Occupational Therapist in your community.

SECONDARY CHALLENGES

Secondary challenges are not caused by being exposed to alcohol while in the womb. These challenges develop throughout life when a person's disability is not recognized and supported. Living in an environment that is confusing, overwhelming, and frustrating can lead to some of these issues.

Below are some of the secondary challenges that people with FASD may experience when their disability is not properly supported:

- · Mental Health issues
- · Trouble with the law
- Addictions
- Gambling issues
- Homelessness
- · Problems with employment
- · Not completing school
- · Risky sexual behaviour
- Social isolation
- Victimization

When people with FASD receive the support they need, it can often help avoid the development of these secondary challenges. Supports are also available to help people who may experience these challenges. There are services in many communities to help with any of these issues, you can talk to a family member or a support person about finding supports and services to help.

The important thing to remember is that secondary challenges are one of the many reasons why people with FASD need support. Keep in mind that there is help and that people with FASD can lead happy, successful lives.

ADVOCATING

FASD is a disability that is not very well known and is often misunderstood. Because of this, people with FASD often need to advocate for services. Advocating means to support or argue for a cause. Most often the cause people with FASD are arguing for is their need to access supports and services.

Unfortunately, people with FASD might also need to advocate because FASD is a disability that is associated with a lot of stigma. Stigma means that people have incorrect beliefs about FASD, they have received untrue information about the disability, or they have only heard negative things about people with FASD. This is why a big part of advocating is helping to educate other people on what life with FASD is really like.

There are many different reasons or places that people with FASD might have to advocate. Someone might advocate to access services like getting a mentor or to have things changed to meet their needs, like having more time to take a test in school or getting a later start time at work.

The first step in advocating for yourself is telling people that you live with FASD. Sharing information about your disability can help people understand your needs. But it is completely your choice who you tell and when you share information about your disability. If you feel uncomfortable telling someone, you don't have to tell them.

It may take time and practice to become comfortable speaking about your disability. Here are some tips that may help.

- People may not know what FASD is so when you tell them you live with FASD, you may have to explain what the disability is. The FASD Network has books that explain what FASD is, you can contact the FASD Network and bring these books with you to help educate people about FASD (call 1-866-673-3276 to get a book about FASD).
- · When you explain your disability to people make sure you tell them your strengths, not just your struggles.
- · If you are nervous or unsure of what to say, you can write things down the night before.
- · Sometimes it's a good idea to bring a support person with you. This can be a family member, mentor, or support worker who understands what your needs are.

STRENGTHS

There are supports and strategies that can be used for every struggle discussed in this book. Changing things to meet the needs of people with FASD is important to help them succeed in life. In order to understand what kind of changes to make, we need to discuss the struggles that they experience. It can be very difficult to read or listen to a list of the struggles you may have.

Just remember that FASD does not define you. Every single person with FASD has amazing talents and strengths.

Here are just some of the strengths that are common for people with FASD:

· Friendly

· Verbal

· Helpful

· Caring

· Artistic

· Hands-on

· Cheerful

· Creative

· Athletic

· Generous

· Outgoing

Curious

· Energetic

Hardworking

Spontaneous

· And much more!

When you're creating strategies for your struggles or advocating for support, try to keep your strengths in mind. A strength-based approach to support draws on the strengths of the person with FASD and the strengths of their support team.

For example, Josh just started a new job. Usually when someone new starts they spend the first 3 days watching training videos. Josh knows that because of his FASD he may not be able to pay attention and learn from videos. Josh explains this to his new boss, Josh also explains that he's a very hands-on learner. To help Josh his boss decides to use his strengths. He asks a co-worker to be Josh's mentor and teach him how to do the job as they go so Josh can learn in a hands-on way.

THE FASD NETWORK

The FASD Network (known as the Network) is a community-based, provincial organization with offices in Saskatoon and Regina. Through support, training, and events the Network provides services to individuals and families from any community in Saskatchewan.

Support Program

Through our Support Program, we provide services to give individuals and families direct support in their daily lives. Using their in-depth understanding of FASD, our Support Workers provide individualized support and one-on-one assistance to meet the unique needs of our clients.

Our Support Workers work with the individual or family to create short-term goals and determine a plan to reach these goals.

Services offered:

- One-on-one support
- Education on FASD
- · Strategies for living with FASD
- · Referrals to community programs/services
- · Advocacy for support and services
- · Development of life skills
- · Access to peer support
- · Assistance with diagnosis and assessment
- · Support services during involvement with the justice system
- · Support services during involvement with Child Family Programs
- · Assistance navigating systems such as school, health, income support, social services, justice, etc.
- Assistance accessing the Cognitive Disability Strategy

To access support please call the Network at 1-866-673-3276 or email info@fasdnetwork.ca

FASD NETWORK OF SASKATCHEWAN

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