

I AM A CAREGIVER!



FOR A PERSON WITH FASD

CAREGIVER RESOURCE GUIDE



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WELCOME TO...

YOUR CAREGIVER RESOURCE GUIDE!

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This document was created with caregivers in mind and this includes families, relatives and all those engaged in this important work. We know that children and youth with FASD require consistent care and support and we hope this guide is a helpful document. We believe that supporting children as early as possible has important influences on the life course and we encourage you to get the support you need along the way. This work is based on collective knowledge of training and education in the area of FASD and we acknowledge educators in this field. Please feel free to print this resource and share with your network.

Reference

Badry, D. & Hickey, J. (2018). I Am a Caregiver for a Person with FASD: Caregiver Resource Guide. CanFASD Research Network. Online: www.canfasd.ca

FINDING SUPPORT

BUILDING A COMMUNITY

Caring for an individual with FASD can be both tremendously challenging and rewarding. Whether you are just embarking on the caregiving journey or have spent many years providing care, it is important to find sources of support.

Often times when friends and family think of support, they think of the person with FASD, but building a community of support around the caregiver is equally important. You can play a role in building this community by letting professionals, family, friends and other supports know what your needs are as a caregiver and how they can help support you.

Types of support available to you may vary based on where you are located and the assessed needs of the individual you are caring for. On this page you will find a few suggestions on the different sources of supports that may be available to you.

SOURCES OF SUPPORT

Family

Immediate and extended family members.

Friends

Personal and family friends, as well as friends of the individual you are caring for

Online

Online communities for caregivers, including social media groups and forums.

Respite Carers

Individuals and associated professionals involved in providing respite care.

Professionals

Professionals involved in the individual's care team: doctors, social workers, psychologists etc.

IN NEED OF MORE SUPPORT?

If you find yourself struggling in your caregiver role, reach out for additional supports. Below are some recommended resources where you can find help if needed. We have included a space for you to record important numbers below.

Professionals - Medical and social services professionals may have access to additional caregiver resources

Disability Organizations - FASD is a life-long disability. Consider reaching out to disability organizations in your area to discover what services are available.

Crisis Teams - Crisis phone lines and mobile crisis teams can provide emergent support if needed.

Important Numbers:

LIFE WITH FASD...

EVOLVING CHALLENGES & DEVELOPING OPPORTUNITIES

Age 0-2

CHALLENGES

- Sensory integration issues including aversion to touch, light and sound are common.
- Failure to thrive due to feeding difficulties
- Significant difficulties in emotional regulation
- Sleeping patterns do not develop normally
- Major developmental milestones are missed.

In a stable home with the support of my caregiver I can begin to develop healthy attachment to others. With the support of early intervention and occupational therapy programs I can begin to develop language and motor skills. I can use my developing skills to show you what I like and dislike.

OPPORTUNITIES

Age 3-5

CHALLENGES

- Problems learning and understanding language
- Children are easily overstimulated
- Struggles with transitions and activity changes
- Hyperactivity
- Oppositional behaviours
- Difficulties in learning through consequences

With patience and understanding from my caregiver I can learn to go to my caregiver when I need help.

As my caregiver learns my cues, we can work together to help me regulate my emotions and manage my behaviours.

OPPORTUNITIES

Age 5-10

CHALLENGES

- Struggles in school due to inattention, hyperactivity, language difficulties & behaviours
- Difficulties in planning and following routines
- Major sleep problems
- Sensory issues and environmental sensitivities

With a consistent, predictable routine and some environmental modifications I can begin to develop my skills in regulating my emotions.

In a supportive school I can make new friends and learn to ask my teacher for extra help if I need it.

OPPORTUNITIES

OVER MY LIFE, THE CHALLENGES I FACE WILL EVOLVE.

Age 10-13

CHALLENGES

- Children with FASD are easily influenced by peers
- Behaviour issues escalate and may include theft, lying and physical violence.
- Significant social difficulties, including underdeveloped regulation skills.

In a stable environment with consistent expectations I can learn boundaries and learn how to manage my behaviours

Supported by my caregiver, I can learn social skills and begin to learn to regulate my own emotions.

OPPORTUNITIES

IN EVERY CHALLENGE,
THERE WILL BE AN
OPPORTUNITY.

WE WILL BOTH NEED
SUPPORT.

Age 13-15

CHALLENGES

- Getting a job and having access to money becomes important to many youth
- Dating becomes common amongst like-aged peers
- Struggles with abstract concepts like money and time

With my caregiver's encouragement I can discover my unique talents.

With my caregiver's help I can continue to develop at my own pace.

In a supportive school I can learn and grow.

OPPORTUNITIES

Age 15-20

CHALLENGES

- Sex, drugs and alcohol
- Continued struggles with impulse control, planning and understanding abstract concepts (math etc.)
- Escalating oppositional behaviours
- Depression and other disorders may appear
- Reach legal adulthood yet immature

With help from my caregiver I can learn how to manage peer pressure

I can find my own talents and develop my abilities in the activities I love.

With support I can work at a job or I can volunteer to help others.

OPPORTUNITIES

BUT TOGETHER...

...WE WILL

THRIVE!

Adulthood

CHALLENGES

- Adults often appear more competent than they are
- Difficulty holding employment
- Involvement with the legal system
- Unintended pregnancy and parenthood
- Continued risky/impulsive behaviours
- Addictions

I can continue to connect to friends and family to live a full and rich life.

With support I can have a job or volunteer role that gives me a sense of accomplishment.

With guidance I can make positive choices.

OPPORTUNITIES

SENSORY ISSUES

PERCEIVING THE WORLD DIFFERENTLY

Sensory Problems

FASD has been called a disability of thinking, but it is also a disability of perception and regulation as well. For many individuals with FASD, these differences in perception and emotional regulation can be a challenge.

As a caregiver, it is important to understand how these differences in perception and regulation impact the individual's life. Part of your role as a caregiver will also involve helping others understand these sensory and emotional differences. Many of the issues arising from sensory problems can be managed by modifying the individual's environment.



Understanding the world: Processing sensation

Our brains are constantly receiving information from the world. Most of this information comes to us via our five senses: sight, smell, sound, touch and taste. Try this experiment: sit back for a moment and take a moment to become mindful of each sense, one at a time. While you were reading you may think you are only seeing the page, but as you start to pay attention to your sense of sight you should notice that your peripheral vision is filled with other items in the room. Try the same exercise with touch. While you were reading you may have only noticed the feeling of the pages in your fingers, but as you start to think of the rest of your body you may begin to notice how your arms are resting on the chair or how your feet feel planted on the ground. You may even notice how the neckline of your shirt feels.

What other things did you notice during that exercise? Did you notice as you paid attention to one sense you received less information from your other senses? This is an example of how our brains filters out things that are less important and helps us to manage the constant flood of sensory information we receive.

Now imagine that you were unable to filter out the irrelevant information. For many individuals with FASD, this is a daily reality. Sensory processing problems are a common concern for those with FASD and can significantly impact the individual's ability to navigate the world. On the next page you will find some of the symptoms of the two different types of sensory problems common with FASD and some suggestions on how to manage these sensory challenges.



SIGNS OF SENSORY DIFFERENCES

Hypersensitive individuals are “overwhelmed” by the world

- Bothered by smells that others don't notice
- Finds physical touch unpleasant
- May be very bothered by clothing tags or certain fabrics
- Becomes upset with hair brushing or tooth brushing
- Easily overwhelmed by groups or busy environments
- Complains about sounds that don't bother others
- Bothered by bright lights or bright colours
- Hyper-vigilant (tense, always on alert) or anxious
- May try to avoid stimulation (covering head with blanket or shirt, covering ears with hands etc.)
- Become upset with changes in the environment and may try to “control” their environment to keep it from changing
- Often seen as easily upset, fussy or “high strung”

Hyposensitive individuals are “underwhelmed” by the world

- Does not seem to notice when touched
- Does not notice smells, sights or sounds that others notice
- May struggle with recognizing bathroom urges
- Does not respond as expected when injured (i.e.: does not cry after an moderate or serious injury)
- May seem disinterested or passive (does not receive positive reinforcement from sensation so there is little motivation for interacting with the world)
- Plays excessively rough or seeks stimulation by knocking into things
- May exhibit repetitive behaviours for stimulation (rocking, spinning, head-banging, rolling etc.)
- Stimulation-seeking self harm behaviours
- Boundary issues (intrudes on other's space, interrupts when speaking or makes unwanted physical contact)
- Often seen as disruptive

MANAGING SENSORY DIFFERENCES

Hypersensitivity

- Add ‘dimmer switches’ to lights or use curtains to block bright lights and turn down brightness on computers, TVs and other “screens”.
- Try “sensory friendly” clothing – typically seamless, tagless and seamless. Full lines of sensory-friendly clothing can now be found online.
- Avoid fluorescent lights
- Use noise-cancelling headphones in noisy places, giving the individual control over when they would like to use them
- Manage schedules to provide many breaks from activity and stimulation
- For older children and adults, decide on a word or signal the individual can use to alert you if they need a break
- Give the individual a space they can control (i.e.: a bedroom) and help them to set it up to be a calm and safe space
- Prepare individual for changes well in advance, giving many warnings before transitions

Hyposensitivity

- Weighted blankets or weighted vests may provide pleasing sensory input. Weighted clothing and blankets are commonly available online.
- Provide sensory toys and/or activities with strong sensory inputs and rewarding sensations (bright lights, sounds, music, unique textures etc.)
- Provide extra positive reinforcement for interacting with the world
- Swinging, sliding and activities requiring movement can provide additional stimulation
- Speak loudly (speak from your diaphragm, not yelling) and clearly
- Increase interactions involving physical contact and pay attention to the contact the individual prefers
- Provide opportunities to experience foods with stronger flavours
- Limit ‘screen time’ and choose activities that involve more interactions with others
- Seek medical help to manage concerns of self-harm or dangerous behaviours

SLEEP AN IMPORTANT PART OF WELLNESS



Research has shown that individuals with FASD often experience significant and chronic sleep disturbances that can impact cognitive functioning, behaviour and daily activities. In one study of 100 caregivers who were caring for children 5-8 years of age, common sleep concerns included delayed sleep onset (it was reported that children took 59 minutes, on average, to fall asleep each night), waking more than twice during the night (over half of children), night terrors (almost one quarter), child feeling tired during the day and, more rarely, night terrors (episodes of intense fear which may also include screaming or flailing that occur during sleep).

Sleep disturbance does not always look like sleepiness during the daytime. Difficulties in emotional regulation, behavioural difficulties, hyperactivity and mood disorders can all be signs of sleep disturbances; however, it is also important to note that individuals with FASD may have these difficulties even when sleep issues are not seen.

It is important to note that research has found that sleep disturbances in children with widespread neurological damage, such as that seen in children with FASD, often require intensive interventions to correct severe sleep problems and sleep hygiene measures may not be as effective as they are for neurotypical children. However, because children with FASD are often hypersensitive to stimuli, sleep hygiene measures can help to reduce the overall amount of distracting stimulation in the child's environment and practicing sleep hygiene as a caregiver may also help your own sleep to become more restful. If the person you are caring for is struggling with moderate to severe sleep disturbance it is important to address this issue with medical professionals.

Sleep "hygiene" refers to a set of practices (including both behavioural and environmental factors) that promote restful, high-quality, sleep. While sleep hygiene is not enough to fix a serious sleep disorder or major sleep problem, practicing good sleep hygiene can be helpful for minor issues and is complementary to treatment for most major sleep concerns. For individuals with FASD, the biggest benefit of sleep hygiene is it promotes establishing a regular routine and structuring the sleep environment for success. Since scheduling and environmental modification are common strategies in addressing the challenges of FASD you may find that even if practicing good sleep hygiene does not solve all of the sleep program it adds another layer of stability into the daily schedule. Many of the sleep tips we provide on the next page come from sleep hygiene suggestions!

Remember! The individual you care for is not the only one who needs sleep! As a caregiver you face many demands on your time and energy each day. Being attentive to your own sleep quality and taking steps to promote a restful sleep for yourself each night is an important component of self-care. If you find yourself struggling with sleep difficulties you may wish to talk to your own doctor.



10 SLEEP PROMOTING HABITS

Limit noise in the bedroom

For individuals with FASD, hypersensitivity can mean that even very quiet or sporadic noises are enough to prevent sleep or wake the person up. When looking to limit noise in the bedroom, remember that noises you may not notice may be very noticeable to the person you are caring for. Consider removing clocks that tick and, if the person you care for notices the noise of certain electronics, remove those from the bedroom space as well.

If you can't sleep, get up and do something else

Sleep is often a funny thing and the harder you try to sleep the more elusive sleep becomes. If you cannot sleep, get up and go to do something relaxing in another room (preferably something that doesn't require a lot of bright lights). Give yourself permission to enjoy this other activity and not to go back to bed until you feel tired. Once you feel sleepy, head back to bed and try again. If using this technique for the person you care for, set up a space with quiet, low-energy activities and restrict access to items involved loud, bright or highly active activities.

To nap or not to nap?

Naps for infants and young children are normal, but whenever possible try to schedule naps so they are not close to the child's natural bedtime.

For older children and adults who struggle with sleep problems, napping is not a good idea. Much like artificial light, napping changes the natural production of certain sleep-regulating chemicals in the body, so skipping the nap may help promote a better nighttime sleep.

Stick to a schedule

Our bodies run on an internal 'clock' or rhythm. By waking up and going to bed at the same time each day you regulate the body's internal 'clock', which will help with falling asleep.

Develop a bedtime ritual

Choose "winding down" activities that promote calmness and relaxation. Choose these activities based on the individual person, because while one person may find a warm bath to be very relaxing, another person may not.

Limit pre-bed screen time

The bright white light emitted from many electronics can make it difficult for some people to fall asleep. There is some evidence that artificial light changes the natural production of certain chemicals involved in the sleep/wake cycle. There are a number of "blue light filter" screen protectors and apps to reduce the impact of artificial light on your sleep/wake cycle. Some people find these blue light filters to be effective while others may need to avoid screen time all together before bed.

Avoid alcohol, cigarettes and big dinners

Alcohol and cigarettes interrupt sleep. A large rich meal can also negatively impact sleep. For bedtime snacks, choose small, light foods and serve about 45 minutes before sleep time.

Limit light pollution

Blackout curtains may be helpful for light sensitivity. Look for other tiny sources of light, including LED clocks and electronic items with displays/button lights (DVD players, televisions etc.) and remove these items from the space as well.

Exercise

Exercise a few hours before bed is a great way to build sleep drive in those who have trouble falling and staying asleep. Keep in mind; however, that exercising right before bed could lead to more difficulties in falling asleep, so you should make sure to finish up your exercise a couple of hours before it's time to sleep.

Avoid caffeine

Adults should avoid caffeine before bedtime. Children and those who are extra sensitive to the effects of caffeine should try to avoid caffeine entirely.

ROUTINES

FOUNDATIONS FOR STABILITY

Stable routine is important for all children, but a regular routine can be especially important for an individual with FASD. Children and adults with FASD struggle with “central executive” functions, including planning and impulse control. Developing a predictable and stable routine at home helps the individual to remember tasks of daily living (through repetition and reinforcement) and may also help individuals who struggle with change or transitions to accept these things more easily. By building a predictable routine into the day you have the ability as caregiver to warn of upcoming changes and the individual is able to predict what activity will come next.

In many households routines are something that become established naturally. You get used to going to work at a certain time, eating dinner at a certain time, watching your favourite shows etc. You may not even notice these routines until they are disrupted (if your shower is broken you may notice that you have trouble remembering other items that you do after your shower, for example). Unfortunately, the neurological damage that occurs with FASD often impairs the ability of individuals to form these natural routines. This can cause the individual appear disorganized, struggle to remember tasks and have difficulty with time management. It is important to remember that these behaviours are not caused by willful disobedience – they are a result of a disability of thinking. Rather than relying on a routine to ‘just happen’ it may be helpful to carefully structure a routine and to create visual reminders throughout the home to help everyone remember what needs to be done. If you are caring for a child, invite them to help create visual reminders by cutting out photos or choosing clip art pictures that remind them of each task. If the individual you care for is an adult they may prefer written post-it notes or a small wallet card as reminders.

Regular routines need not be full-day routines! Building specific routines or rituals into parts of the day (for example: “going to bed”) can be very helpful for individuals who struggle with memory or those who have difficulties with time management. Setting up miniature routines throughout the day also provides you as a caregiver the opportunity to recognize and reward success more frequently. Breaking up the day into smaller routines offers many opportunities for “do overs”. If one routine is not completed, you and the child or adult with FASD have several more opportunities to make a correction and succeed.

Recognizing and rewarding success are an important part of reinforcing routines. When deciding on a reward, it is important to consider what the individual you are caring for will find rewarding. Adults and older teens may enjoy regular verbal recognition while others may prefer earning larger rewards that happen less often, like dinner at a restaurant. For children a token economy could be an effective option. In a token economy the child earns desired items or privileges through successful task completion. Token economies can be adjusted to reflect the child’s age and abilities. Very young children will likely respond better to immediate rewards (such as a piece of candy or time with a desired toy) while older children may prefer earning stickers, marbles or money that they can ‘cash in’ for larger desired rewards. When using larger rewards, set up reminders in prominent places to help your child remain motivated to earn the reward. You can learn more about token economies on (PAGE).

PLANNING FOR SUCCESS: CREATING ROUTINES

Creating a structured routine sounds easy, but it can be easy to forget small tasks that you automatically do without thinking about them. When creating routines for a household that is home to an individual with FASD every task, no matter how small, should be included on the routine. Remember: individuals with FASD think differently, so what you may see as an obvious or logical next step in a routine may not be as obvious to someone with FASD.

Whenever possible, consider involving every member of the family in creating routines and reminder items. If you are helping an adult create routines, give them as much responsibility as possible in the process. The more involved the individual is in creating the routine the more likely they are to feel positive about the routine and want to follow it.



STEPS FOR CREATING A FAMILY ROUTINE

1. Decide what part of the day you want to set the routine for (i.e.: “Going to bed”).
2. Walk through the routine slowly and deliberately, taking note of each step as you go. This step can be a fun stage to involve children by creating a game in which each child tries to remember the next step in the routine as you walk through it.
3. Test out the routine as a family to make sure you have everything written down. Make any adjustments you need at this stage!
4. When you have the steps written down, decide where reminders should be posted. If your routine moves through the house you may need a few reminders. Reminder sheets could be posted on the walls or you can create laminated pages that can be drawn on with whiteboard markers.
5. Start following the routine. Depending on the abilities of the person you are caring for, you may need to help them walk through the routine several times before they are confident to try and use the reminder items on their own. Patience and practice are key!

LOOKING FOR MORE?

Check out 25 for a visual routine template!

EATING A SENSORY EXPERIENCE

For a child or adult with FASD, eating can be an area of challenge. The following information is intended for caregivers who are providing care to children or adults who are of normal weight, but experiencing minor challenges in terms of eating and diet. If the child or adult you are caring for is severely impacted by eating difficulties, overweight or underweight they will need more intensive support in this area. Many professionals, including pediatricians, physicians, dieticians, nutritionists and occupational therapists may be involved in addressing eating challenges. Challenges related to eating and nutrition can have serious impacts, so please consult with the care team should you have concerns in this area.

Help! I have a picky eater!

Feeding a “picky” eater can be a very frustrating experience, but there are some important things to remember when approaching “picky” eating from an FASD-informed perspective. First, many children who are picky eaters are often thought of as being willful, stubborn or defiant when they refuse to eat certain foods. Adults who are highly food selective are often thought of as being inflexible, stubborn or attention-seeking. While so-called “picky” eating can be a result of oppositional behaviour or resistance to new experiences, for children and adults with FASD it is important to remember that this is not always the case.

Many individuals (both children and adults) with FASD struggle with hypersensitivity to sensations, including taste, smell, sight, hearing and touch. Eating is one of the rare activities that actively engages all five senses in the experience. Looking at a delicious plate of food, smelling the aroma, the taste and feel of the food inside the mouth and even hearing the satisfying crunch of a vegetable as it is bitten are all key parts of the eating experience. For those who do not experience hypersensitivity, this total sense involvement is one of the things that makes eating so pleasurable! Unfortunately, for individuals who struggle with hypersensitivity or those with sensory integration problems the eating experience can be downright unpleasant.

Imagine a world of hypersensitivity (increased sensitivity). The crunch of a carrot is so loud it vibrates through your head, textures are unpleasant, colours are bright enough to hurt your eyes and instead of a single delicious smell from your meal you smell five different strong smells that just won't mix together. How would this change your approach to eating? For an individual with FASD who struggles with hypersensitivity, being “picky” about foods may be a way of protecting themselves from the unpleasant experiences associated with hypersensitivity. For those with hyposensitivity (reduced sensitivity) eating can be just as challenging. Food doesn't smell appetizing and tastes bland. Textures blend together, providing little to no tactile interest. How would this change your eating experience?

As mentioned earlier, in some cases “picky” eating can also be an oppositional response. Individuals in care (especially children) often have limited amounts of control over their lives, but food is one thing that they can control. If sensory issues are not suspected and you are caring for a child or adult with severe selective eating, you may need to seek assistance from a psychologist or therapist that is familiar with disordered or selective eating. They can help you to develop an intervention for your family that addresses the source of the eating concerns.

OTHER EATING CHALLENGES

Understanding how sensory difficulties can impact eating is an important part of caring for a person with FASD, but not all eating difficulties are a result of sensory issues. Below you will find some of the other factors that may contribute to eating challenges.

Muscle weakness

Particularly in young children, muscle weakness can be a major contributor to eating difficulties. Children with muscle tone deficiencies may struggle to eat many foods. Hypotonia (low muscle tone) can cause the individual to become fatigued when chewing (infants may tire quickly when bottle feeding) or the person may have difficulty sitting for the entire meal.



Lack of coordination

A lack of coordination can contribute to eating difficulties in many ways. Children with FASD may struggle to swallow properly due to an inability to coordinate all of the muscles involved in swallowing. Individuals who struggle with coordination may also become frustrated when eating with utensils. Those who struggle with coordination are often messy eaters and have difficulty keeping food on their plate or moving food to their mouths without spilling. A lack of coordination can also cause eating to take much longer, so if meals must be consumed in a restricted amount of time the person may be unable to finish their food.

In addition to frustration, a lack of coordination can be a cause of embarrassment. If the individual recognizes that they are messy when eating they may avoid eating in front of others or may eat very slowly to try and minimize spills.



Distraction

Meals are often a social occasion, but this social setting can be a major distraction for an individual with FASD. Managing distraction at mealtime may take some advance planning and help from others at the table. Use gentle reminders and prompts to bring attention back to eating and remove tempting distractions, like television, from the eating space.

EATING STRATEGIES FOR SUCCESS

Understanding how the experience of eating may be different for a person with FASD may help you as a caregiver feel more empathy, but a balanced diet is still an important focus of care! Below you will find some ideas on working with “picky eaters”. Remember though: Significant issues with selective eating should be addressed with the care team!

Think about texture

Texture is a huge part of eating. The good news is that many foods can be served in different ways that produce different textures. Cauliflower, for example, can be eaten raw (crunchy), steamed (firm but not crunchy) or even whipped like a mashed potato (smooth). Some individuals may not like mixing textures in their food (lumpy mashed potatoes, for example).

For children or adults who avoid certain textures, find ways to incorporate healthy foods into more appealing textured-products (adding extra pureed vegetables into a sauce, making a cauliflower-based pizza crust or using specialty pasta made from lentils instead of flour, for example). While coming up with clever ways to transform healthy foods used to be a huge challenge, today the internet is a great source for both recipes and specialty products.

If at first you don't succeed... don't give up!

Tastes change across the lifespan and it can sometimes take several exposures to a new food for someone to ‘develop a taste’ for it. Think back to your childhood. Were there any foods you disliked then that you enjoy now? Keep offering new foods in various preparations. If possible, try pairing the new food with a really loved food, like putting a new vegetable onto a delicious homemade pizza.

Get everyone involved in food preparation

Find ways to get the person you are caring for involved in the preparation of foods, especially new foods that they may be reluctant to try. Helping to prepare food not only gives the individual more exposure to the new food, but it also gives them a sense of accomplishment in making the dish, which encourages them to try to dish once it is done.

Give children a chance to experience a new food freely

Eating is a sensory experience and for some young children, including many children with FASD, sensory exploration of food is an important part of accepting food. It is not uncommon for younger children to use their fingers to touch and experience food. While many caregivers feel the urge to correct the child and encourage the use of utensils, for a picky eater it may be helpful to allow the child to use their fingers to pick up the food. Even if the child doesn't put the food in their mouth, they will get a chance to taste the food on their fingers.

Allow ample time to eat

Many children and adults with FASD eat more slowly. This can be a result of sensory integration problems, muscle weakness, coordination problems or simply distraction (they wind up talking to others at the table instead of eating). Allowing extra time for eating will help compensate for some of these issues.

Have only good choices available

As a caregiver part of your role is to set the individual you care for up for success. Keeping a wide variety of healthy foods in the house and minimizing access to unhealthy choices is a great way to give structured independence. Create ways that the person you are caring for can have choices but where those choices are set up with only good options. For example, having a 'snack box' in the fridge that contains a variety of fruits, vegetables and other healthy snack items and allowing the person to choose any snack they want out of the box or offering a choice between two different vegetables ("would you like broccoli or green beans?") for dinner.

Not all people like all foods

When encountering a "picky" eater, it is an easy trap to fall into to assume that all food refusals are a result of being "picky" rather than a legitimate dislike. Even the most adventurous eaters will eventually encounter a food they just don't like. If there are a few foods that don't seem to work no matter what you do it may simply be a case of "I just don't like watermelon". If this is limited to a few foods and not having a major impact on your child's overall diet it shouldn't be a problem to replace the disliked food (watermelon) with another option (cantaloupe).

Allergies and intolerances

Food allergies can come in many forms. While many people think of allergies as only resulting in medical emergencies (like anaphylaxis with peanut allergies), allergic reactions and intolerances to food can also include things like rashes, stomach upset, vomiting and diarrhea. Individuals with FASD may struggle to make the connection between certain foods and how they are feeling, so they may not be able to identify a food that is problematic. As a caregiver, if you notice certain physical or behavioural reactions to certain foods it is advisable to speak to the individual's doctor as allergy testing or dietary restrictions may be recommended.

Make new foods fun

If introducing new foods or eating a variety of foods is a challenge for the person you care for, consider ways to encourage accepting new or varied foods through games, family challenges or other fun and interactive activities. For example, children can be encouraged to "eat a rainbow" by eating at least one fruit or vegetable from each colour of the rainbow each day. Create a magnetic board or wall chart to track how much of the "rainbow" is filled in each day. If needed, you could add a reward at the 'end' of the rainbow that can be earned by filling in all of the colours.



MAPPING FUTURES

THE LIFE DECADES MAP

For a person with FASD, life will bring many challenges, but with support and guidance those challenges will also bring many opportunities for growth. Many individuals with FASD will grow up to live fulfilled and meaningful lives.

Caring for someone with FASD not only involves helping them meet challenges as they arise, but also thinking ahead to the challenges that are further down the road. While the focus for caregivers is often on planning for future challenges, planning for future goals is equally important.

The life decades map shown on the next page is a visual representation of the lifespan. It can be used in number of ways. Below you will find a few suggestions, but you should feel free to come up with your own unique uses for this resource.

Goal Setting

For an person with FASD, goals may look different or happen at different times. As you work through this goal setting activity, involve the person you are caring for as a way to develop plans together.

In the purple section of each decade, write down important goals to accomplish. In the blue section, write down the resources or supports you will need to accomplish those goals.

Reframing Expectations

A diagnosis of FASD brings many changes. Amongst these changes is a shift in expectations. For some families, this may mean leaving behind some expectations in order to build new hope.

Using the life decades map can help with building new hopes and goals. In the blue section, write the expectations you are leaving behind. In the purple section, record new hopes and goals that you will work on together.

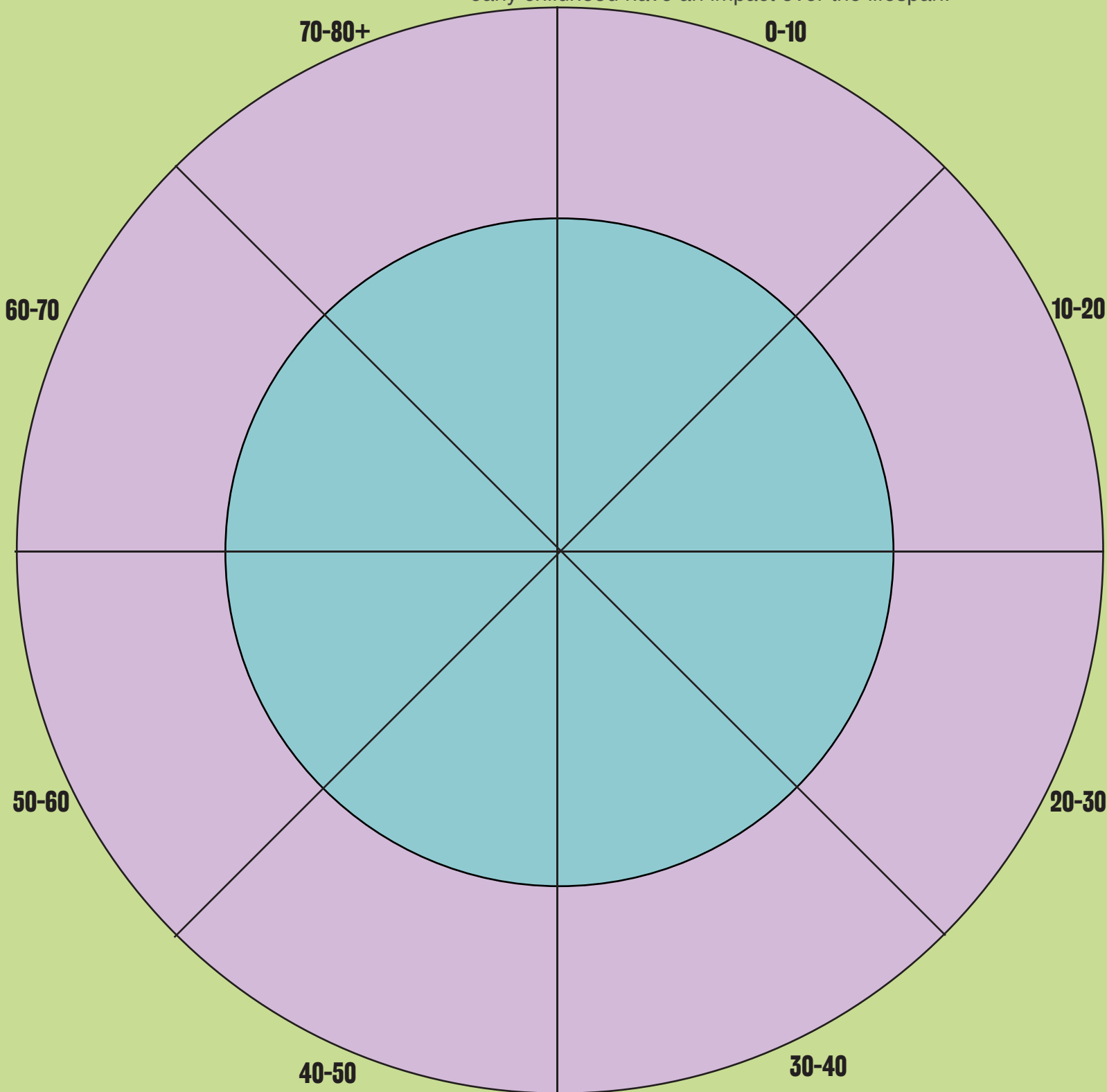
Strengths-Finding

Think about some of the strengths of the person you are caring for and make a list of these strengths. Do the same for your strengths as a caregiver. If desired, you can also do the same for other family members.

In the purple section for each decade, write down how the individual's strengths will help them to accomplish important milestones. In the blue section, list how your own strengths will help you ensure the person is cared for during this time.

CREATE A LIFE DECADES MAP

Create a sample life decades map below for the individual you are caring for. As you move around the circle from decade to decade, enter potential challenges into the blue section for each decade. For example, permanency planning might be entered into the 10-20 year decade. In the purple section, list your hopes or goals for the individual in that decade. If it is helpful, you can also record ideas in this section on how to accomplish these goals. A life course perspective invites reflection that decisions made in early childhood have an impact over the lifespan.



WHAT'S WORKING?

BUILDING ON STRENGTHS

Take a moment and think about your role as a caregiver for a person with FASD. If someone asked you to sum up the caregiver's role with just a single goal, what would it be? For many caregivers, the end goal is to help the person with FASD achieve a life that is meaningful. To "be all they can be".

"Being all you can be" is a big goal, and for a person with FASD the road to that goal will be filled with challenges, but that same road leads to the discovery of many strengths. Unfortunately, FASD is often framed in terms of what the person cannot do, instead of what they can do. It is important to have realistic expectations and know some of the limitations that FASD may bring to a person's abilities – these are needed to help the rest of the world understand how to support the person in the community. But just as important as understanding what an individual with FASD can't do is understanding what they can do. Caring for a person with FASD is not just about managing what doesn't work, it is also about encouraging what does work.

Imagine life like a pie graph. Things that work fill one section of the pie and things that don't work fills the other section of the pie. Yes, making the section of "things that don't work" smaller is a great goal, but what do you replace that section of the pie with? Now imagine instead that you make the "things that do work" section bigger by filling more of the individual's life with those things – if the pie is filled with things that work pretty soon there's a lot less room for the things that don't work. Think of a common goal like "eating healthy". Is it easier to eat healthy if you have brownies in the fridge and remind yourself that you cannot eat brownies or would you be more successful if you filled your fridge with fresh, healthy, appealing foods (instead of brownies) and had lots of good choices to pick from every time you went to look?

Recognizing and encouraging strengths is one of the most important things a caregiver can contribute to the care team. Other professionals will often be focused on what is not working, but by drawing their attention to what is working or what the individual can do may lead to some creative solutions. For example, with the support of her caregiver Liz Kulp, a young lady with FASD, wrote a book about the impact FASD had on her experiences growing up called "The Best I Can Be". Liz struggled with writing but had a unique perspective on her experience, so her caregiver provided support with writing and formatting the book while Liz focused on capturing her lived experience through hand-written cards that were then printed into the book.

Strengths can take many different forms and it is important not to overlook different areas when looking for strengths to capitalize on. For example, a child who struggles with impulsive behaviour but is able to play a turn-taking game with a close friend is not only showing improvements in self-control, but this situation also says something important about the relationship with that other person. A teenager that doodles elaborate pictures in class might have a problem with focus, but they also are showing creativity and artistic talent. Now instead of just a problem student there is a potential solution available – could more creative components be incorporated in to the student's school plan? Is it possible to create a poster or a video review about a book instead of writing a book report?

Finding Strengths

Strengths are most impactful when shared! Instead of coming up with a list of strengths on your own, share this experience with the person you are caring for. Sit down together and talk about what the person does well and what you, as a caregiver, admire in that person. Talk about how these things might help you meet some of the challenges you face together.

When you have this conversation, consider different ways to bring strengths out within the conversation. Things that may not seem like a big deal can often be a place where lots of strengths are found. For example, if a child states that “they are a good friend”, investigate together what makes a good friend. Are “good friends” caring? Empathetic? Helpful? Adventurous? Brave? Reliable? Fun loving? Does a good friend always have a smile? Do they make you feel better when you are sad? Do they forgive you if you make a mistake? The answers you get may be similar or different, Use the space below to record strengths or work through this activity in a way that makes sense for you.

FINDING STRENGTHS

“SNOW PLOWING”

GETTING AHEAD OF CHALLENGES

Future Ahead!

Caregiving is not only about the moment, it is also about the future. Below you will find two major life stages that require advance planning, but there are many more. Thinking ahead as a caregiver can be thought of as a form of “snow plowing” - you are clearing a path for the individual in advance to make the road ahead easier to travel.

Dating, Drinking and Drugs

The teenage years and young adulthood can be a scary time for caregivers. Youth with FASD often particularly vulnerable to peer pressure. Poor impulse control and a strong desire to be liked can cause youth with FASD to be easily led by friends or peers and pressured into engaging in undesirable behaviours.

Drinking and drug use are common concerns that arise during the teenage and youth adulthood years. As a caregiver, boundaries and behaviour monitoring will be particularly important to protect vulnerable youth from engaging in these behaviours.

Dating is another area where youth with FASD may face challenges. Many forms of media portray unhealthy relationships, so it is especially important to teach the youth or adult how to have a healthy relationship. Youth with FASD may not be ready to date at the same time as their age-similar peers, so consider involving youth in other social activities.

If you are looking for resources to speak with a youth or youth adult with FASD about drinking, drugs or relationships there are many excellent plain-language resources available online.

Thinking Beyond Adulthood

Depending on your caregiving role, you may or may not have a set date where the person you are caring for will transition out of your care. If you are working with a youth in care, a transition plan will likely be developed starting at around age 16. For youth with FASD, a transition plan will need to look at what level of independence is realistic for the individual and what supports will be needed into adulthood. Creating a transition plan will likely involve you, the youth’s caseworker, a transition worker, child and adult disability services and other professionals in the individual’s care team.

If you are providing care to a youth or adult who is not currently under the care of the government, you may not have a set transition date. However, it is still important to consider future care arrangements, particularly if the individual you are caring for will not be able to live independently. Seeking a public guardian or trustee for the individual may be advisable. The office of the public guardian for your area and a lawyer can provide you with information and options in regards to care arrangements for adults. If you intend to seek a public guardian this process must be started well in advance of the individual’s 18th birthday to ensure the individual is not left without support and services.

MY CAREGIVING FUTURE PLAN



Major life event coming up:

What is already in place?

What am I worried about?

What is exciting about this transition?

What supports will we need?

What can be done in advance to 'clear the path' ahead?

SELF CARE

CARING FOR THE CAREGIVER

Self care is not a luxury

Self care is a vital part of providing care to another person. Caregiving means taking on a burden of care for another person. As a caregiver you invest your time and energy (both physical and emotional) into helping another person live the best life possible. When that other person faces challenges, such as those that individuals with FASD face, the burden on the caregiver can be increased, so it is vital that you as the caregiver allow yourself the time and space needed to 'recharge' your energy stores. You cannot provide quality care to others if you are not caring for yourself.



What is self care?

Self care is any intentional action that you, as a caregiver, take to look after your own physical, emotional or spiritual needs.

Self care does not necessarily mean “caring for myself by myself”. In some cases, incorporating elements of your own self care into the family routine (taking a family exercise class, for example) can be an excellent way to look after yourself even when there are competing demands on your time.

Types of self care

Physical - Regular exercise, a healthy diet, quality sleep and medical care are all part of physical self care. Physical self care is one of the most commonly overlooked forms of self care.

Emotional - Emotional care is harder to define than physical care as it will vary for each person. Emotional self care are activities that you do to promote your own emotional wellness through addressing negative emotions or fostering positive emotions. Counseling, conversations with friends and family, journaling and meditation or relaxation exercises are all common forms of emotional self care.

Spiritual - If spirituality is an important aspect of your life, caring for your spiritual well-being should be an important component of your self care routine. Attending religious services, speaking with spiritual advisors and setting aside time for prayer or reflection can all be valuable for spiritual self care.

10 SELF CARE STRATEGIES

Give yourself permission for self-care

Caring for yourself is an important part of providing care to another person.

Self care is not an indulgence, it is a necessity. Part of providing care to another person is ensuring you have the physical and emotional reserves needed to provide great care.

Give yourself permission to engage in self care, knowing this is essential to being effective.

Set aside time in your schedule for self care

Caregiving is busy work! Without a set schedule and protected time, it can be easy for self care to fall to the bottom of the ever-growing "to do" list.

Part of making self care effective is prioritizing self care as an important activity. Set aside time in your schedule regularly for your own self care and protect this time as valuable. Building self care into your personal or family routine can be a good way to provide structure to these activities

Take advantage of Respite Care

Respite care is in place to give caregivers the opportunity to recharge and get a break from the caregiving role.

Take advantage of any respite care made available to you (including offers from friends and family). If things are going well when the scheduled respite time arrives, resist the urge to cancel the respite. Respite can be a good time to get your own errands completed, but make sure to leave time for enjoyable self care activities!

Micro self care moments

Self care can take many forms. While you may find it difficult on some days to schedule a block of time for self care, don't discount the value of smaller self care moments. What can you do in just a couple of minutes to help yourself recharge?

Change the scenery

A change in scenery can change your thinking! When possible, consider taking your self care activities on the road by going for a walk or spending some time at a favorite location.

Yoga and other exercise

When you are tired it can be hard to work up the motivation for exercise, but many people find regular exercise to be an essential part of maintaining balance.

If your caregiving arrangement is not compatible with a solo exercise routine there may be ways to involve the rest of the family. Family fitness nights or family fitness classes can be a great solution to work regular exercise into a busy schedule.

Eat healthy, but appealing, foods

Many people find stress a trigger for unhealthy eating. Stock your fridge and pantry with a wide variety of quick, healthy and appealing foods to ensure you always have a healthy option on hand!

Find a passion

Finding ways to contribute to a cause you are passionate about can be a positive method of self care. Like exercise, this is a form of self care that other family members can also become involved in.

Do what works for you!

Self care is an individual thing. It is all about what recharges your energy reserves, be that going for a run, enjoying a cup of tea with a good friend or watching a favourite television show. When trying new self care activities be mindful about how you feel during and after the activity, filtering out activities that are "time fillers" instead of "rechargers".

Give yourself permission to say 'no'

Caregivers sometimes find themselves pressured to over-commit. If you are noticing your schedule is filling up, don't feel obligated to commit to ever request. Prioritize your own well-being.

"To experience peace does not mean that your life is always blissful. It means that you are capable of tapping into a blissful state of mind amidst the normal chaos of a hectic life."

JILL BOLTE TAYLOR

STRATEGIES

ENVIRONMENTAL INDICATORS

Abstract Concepts

Many people with FASD struggle with abstract concepts such as time. Both children and adults may struggle to understand time and this can lead to difficulties in terms of routines, schedules and even wake-up times. In cases where the person you are caring for struggles with the concept of time, an environmental indicator might be helpful.

An environmental indicator is something placed into the person's environment that gives a some sort of cue or signal (usually visual or auditory) about something that should happen at a particular time. One example that is common to many families is setting a timer when cooking. The timer ensures that even if the person cooking loses track of time that they will be reminded when the cooking time is done.

Examples of environmental indicators are pictured below. The first is a modified wall clock that has sections coloured in to show the individual what activity should be happening when the clock hands are in that section of the clock. The others are "OK to wake" toys designed for young children that glows one colour when the child is expected to stay in bed and another colour when it is time to get up.



The Visual Routine

A visual routine is a tool to help youth and adults who have challenges remembering the order or components of a routine. The visual routine can give the individual more control by giving them the ability to follow the routine without constant supervision and reminders. This visual routine can also be incorporated into a reward program! Rewards can be given out for each routine element or for completing the routine in entirety, depending on the abilities and developmental level of the person you are caring for.

To complete the visual routine below: Come up with a routine for your home, for example “going to bed”. Break the routine into individual components (wash my face, brush my teeth etc.) and write those into the description spaces. Fill in the boxes with photos or clip art that represents each section of the routine. You can involve the person you are caring for in developing the visual routine. Young children can choose pictures or clip art while older children and adults can help construct the actual routine.

OUR ROUTINE: Brushing Teeth

Visual Routine Example



Put toothpaste on the brush



Wet toothbrush & toothpaste



Brush teeth (up and down, side to side)



Spit out toothpaste



Rinse toothbrush



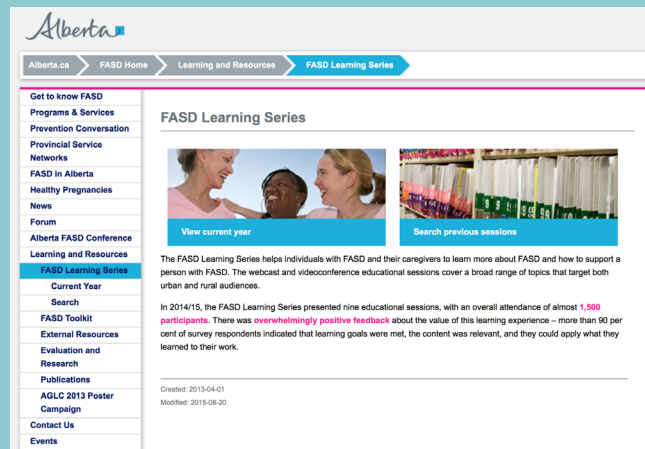
Rinse mouth with water & spit water out

MORE RESOURCES FOR CAREGIVERS

The Alberta FASD Learning Series

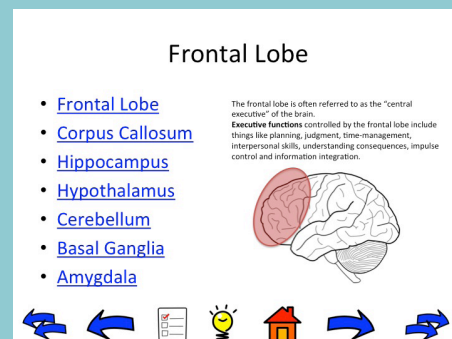
The Alberta FASD Learning Series is a series of online video podcasts featuring a number of experts in FASD. From education to lifespan planning to neurological challenges, the Alberta FASD Learning Series includes dozens of important topics. This resource is available for free at:

<http://fasd.alberta.ca/fasd-learning-series.aspx>



The Caregiver Curriculum on FASD

The Caregiver Curriculum on FASD is a free resource. This multi-module learning curriculum contains an overview on the neurological effects of prenatal alcohol exposure, strategies for caring for an individual with FASD and information specific to the caregiving role.



INFORMATION

IMPORTANT INFORMATION

Keeping records of important information can be helpful not only for you, but for others should you require support in your caregiving role. Use the form below to help record important information that you and others can use to help support the person you are caring for.

Professionals on the care team:

Name: _____	Role: _____	Contact Info: _____
Name: _____	Role: _____	Contact Info: _____
Name: _____	Role: _____	Contact Info: _____
Name: _____	Role: _____	Contact Info: _____
Name: _____	Role: _____	Contact Info: _____

Current Rules and Boundaries:

Important Routines:

Behaviour Strategies:

Other Important Information:

CAREGIVER RESOURCE GUIDE



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