

Strategies Parents Find Helpful In Raising Their Children Living With FASD©



Brought to you by St. Michael's Fetal
Alcohol Spectrum Diagnostic Clinic

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This booklet is dedicated to all the caregivers who contributed their invaluable strategies making this project possible.

Thank
You

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Introduction

Dear caregiver,

The following booklet outlines several strategies that parents have identified as helpful in raising their children living with FASD.

It is important to note that the strategies provided in this booklet are examples of approaches that have worked for individual families and children, and may not necessarily work with your child.

The purpose of this booklet is to allow families insight into strategies other families have found helpful, and will hopefully inspire similar or new strategies that will work with your child's individual needs.

Thank you.

Infants and Toddlers (0-2 years)



Memory

Grocery shopping - I tell her 4 or 5 things that we need and repeat them to her a few times, usually in a sing song voice and then I ask her to remind me what we still need. (age 2)

Visual schedule of days of week to remind them of what is coming up. (age 2)

Falling Asleep

Use calming strategies before bedtime such as reading stories and back massages. (age 1+)

Use consistency [at] night time, and practice patience with the time it takes for the child to feel secure enough to try to fall asleep. (age 1+)

We use white noise machines for both our children. The machines can make different sounds (rain, waves, heart beat etc) but we use mainly the white noise setting. It blocks out other noises in the house and seems to soothe them. (age 0-3)

Infants and Toddlers (0-2 years)



Waking from Sleep

Keep his room scaled down, warm and have quite music on. Cuddle when he wakes up and reassure, but do not talk or put lights on. (age 8 months)

My son used to be horrendous waking up from a nap. I started identifying something fun he wanted to do BEFORE he slept and having a key object/phrase etc attached to that activity to remind him about it when I woke him up. I also would start to wake him up 15 minutes before he truly needed to get up, allowing him to do it slowly. (age 2)

Making Friends

We always review the basics before play sessions i.e. use your words, listen to others words, gentle hands. (age 1 ½+)

Avoid books, movies, TV that demonstrate poor friendships or social skills. (age 1 ½+)

Confabulation

When I recognize what is happening I just look at her and remind her that what she is saying is not really true. (age 2-6)

Infants and Toddlers (0-2 years)



Irritability

He is a very cranky baby and needs a lot of reassurance. I may give him up to 5 baths a day, as he loves the warm water. (age 8 months)

A preventative strategy: we avoid setting any precedents for activities we didn't want to have to deal with repeatedly, such as granting a stop at an ice-cream shop, or permission to open the car windows, or to touch the car's instrumentation. (age 2+)

All Areas in Life

In every facet of life, children and adolescents who have FASD need extra help, extra supervision and lower expectations from their parent(s) or caregivers, teachers and anybody who has anything to do with them. It takes time to accept that love and opportunity and money can't change who the child is. The parent must always be there to advocate, assist, accommodate and advise their child as long as possible without judgment or inappropriate expectations. If in doubt, always expect less rather than more. This is a life long process, not a strategy that can help in a month or a year. One thing about having a child who has FASD is that life is never boring, they'll surprise you with their ingenuity and non structured thinking and you'll see parts of life you never knew existed. (age 6 months+)



Preschoolers (3-5 years)



Comprehension

Read 2 or 3 sentences and ask child to explain what is happening in the story. (age 4-7)

If reading a story that has been read before, make some changes to the story and see if the child catches the altering of the story. Usually I change the names of the characters in a humorous manner. (age 4-8)

Read to them, pointing to each word as you read. Ask what is happening on each page. (age 3+)

When reading stories I point to words as they are slowly being read, and ask the child to repeat after me. (age 4-7)

Writing

Practice printing individual letters and numbers in an attempt to learn the skill of legible writing. (age 4+)

Work with copying the alphabet. Then expand to stringing letters together, [in order] to teach letter spacing. Eventually go on to printing words, practice stringing sentences together, using case letters to start sentences, using periods at end of sentences, [and] then using uppercase for names. (age 4+)



Preschoolers (3-5 years)



Language - Spelling/Letter Recognition

Walking to and from school we do spelling verbally - eliminates fine motor struggles of printing and thus less frustration. (age 3-5)

Look for letters everywhere (sticks that get picked up become “I or T or C”) - both my children are incredibly observant and thus this lets them use that skill to find letters. (age 3-5)

Language – Speaking

Spoke back to child whenever she asked a question or gave an opinion or suggestion. Rephrased, repeated or said phrase correctly, but not in negative way, so she could hear the proper way to say something. Constant reminders to use names of people or objects, “he and she” etc. Sing answers to encourage more talking. Our daughter loves music so [we] tried to incorporate it into a game. (age 3+)

Read a phrase and have child repeat to assist in pronunciation skills. (age 3-7)

Understanding Abstract Concepts – Time & Money

Used a calendar in his room...to cross off days and show concrete length of time until whatever date arrives (birthdays, Halloween, Christmas etc). Now he always knows how to use the calendar and ‘see’ time. (age 5+)



Preschoolers (3-5 years)



Attention Span

Whenever he needs to focus on something, I try to make it happen in a visually boring place. If he is getting dressed I often have him do it somewhere other than his room so he doesn't start playing with toys. I also check on him often, asking how it's going. That is generally enough of a cue to get him back on track if he has strayed. He can only focus on one task at a time, so I try not to give him two or three step instructions. This is difficult for me, but necessary for him to be able to accomplish things without getting worried, flustered or lost. (age 3-4)

Memory

I used flash cards with pictures to assist with memorizing animals, objects, numbers and colors. (age 4-7)

I used scavenger hunts to help child remember where he placed items around the room. (age 4-7)

Repeat, repeat, repeat! (age 3+)

It took him four weeks at age four to learn the colour red. We decided in February he was going to learn his colours. So everyday of the month I dressed him in red. The teacher had to say "X you're wearing a red shirt today. Show me your shirt. It's red. X you're wearing red pants today". (age 4)



Preschoolers (3-5 years)



Memory

My son is quite visual and has an auditory processing disorder, so strategies to help him remember things must be visual. Primarily, I try to have routines, as well as, place items that he needs everyday in the same place. For example, I always put his lunch box on the same place on the table every morning so he will remember to take it to school. Everything from school must also go into a well-made, strong folder that goes in his pack and is always next to his lunch box. (age 5)

For home routines I made up a poster with pictures and arrows, showing how, say, the morning goes. There is a picture of him with pictures of his clothes and arrows from clothes to 'him'. In winter I add a hat, coat and boots to the picture. Then there is a picture of his lunch and folder going into his pack. Then a picture of us getting into the car. I also have an evening set of these posters. It is imperative that things like shoes always are in their spot, otherwise he has a frightful time finding them, even if they are in plain sight. Then he gets flustered and it gets worse. (age 5)

Making Friends

Start conversation or make first move for the child. (age 5+)



Preschoolers (3-5 years)



Self Confidence

PRAISE, PRAISE and more PRAISE! (age 3+)

Falling Asleep

Gentle back, neck and head rubs. Reiki helps too. Realizing she may not be ready to sleep, but being consistent with she must be in her room even if not sleeping. Very little if any stimuli in room. Our daughter has a bed, dresser and chair. Only a few things on dresser. Toys are discouraged and not used as a play room. Painted walls, with stick-ons for a bit of affect. Black out blinds on the window. Very quiet room. Only used for sleeping and rest times. Realizing that sometimes we go to bed and she is still awake, reinforce it is quiet time, time to sleep. (age 5+)

Bad dreams sometimes woke up my child and then his active imagination would take hold and he would be unable to fall asleep again. When he was about 4, a family friend made a dream catcher to catch the bad dreams. This worked for awhile, but the dreams came back after about two months. Then we talked about how a brain needs to get out and play, just like a body does, and the time it can do that is at night. Since my son liked to play fight (little army men), it was easier for him to understand that his brain had to 'play' with scary things too. (age 4-5)

Began using melatonin at age 5. It helps him to fall asleep and once asleep he tends to stay asleep. (age 5+)



Preschoolers (3-5 years)



Toilet Training

Finally realizing she will not do what is asked until she is ready. Reinforce and realize it is okay not to have full control. [Kids] bodies are giving many messages that our kids are unable to interpret at this time. Being consistent with times on the toilet i.e. before and after meals, before going out, right after she gets up in morning, before she goes to bed. Keep [toileting] times as close to a regular time as possible. Reading picture books to increase comfort and time on the toilet. Having lots of underwear and willing to throw [them] out if not up to challenge of cleaning them (depending on day you are having). (age 3-5)

Irritability

Try to think of what is coming up/going on at home, school, with or without friends (if there are any). Remind her we are a part of a family, and how should we talk to each other. Also suggesting, sometimes insisting she go lay down in bed, she does not have to sleep but rest. When she gets up or we get her from her bedroom, remind her we all have times we are not happy, but try our best to talk about issues or be better towards the others in our family. Think about nutrition and what she has eaten/drunk lately. Maybe protein snack/drink will help. (age 5+)

Confabulation

When I recognize what is happening I just look at her and remind her that what she is saying is not really true. (age 3-6)



Preschoolers (3-5 years)



Stealing

Most of our kids do not steal. They take things because possession is too abstract. If it is in someone's hand then it is their possession. But if it is just lying there, then it belongs to no one. Their lack of impulse control causes them to pick up items which catches their eye, and then they usually to forget to...put the item back where they got it from. This is a continuous job of reminding them that if it is not theirs then it belongs to someone else so do not touch. Reinforce to always ask if they can look at something that is not theirs. (age 4)

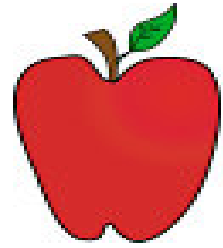
Impulse Control

The most important thing has been to not get angry or distraught when she repeatedly does things I've asked her not to do. If I stay calm and loving then it is easier to redirect her because we are not in opposition to each other. Since punishments and rewards do not work it leaves only love or anger. (age 5)

Alcohol Use

My strategy for keeping my son from trying alcohol, because he's very interested in it, is to not have any alcohol in the house. If it was available, he would try it. And he did once when my older son left a partially used bottle of vodka in the cupboard. Either don't have it or keep it locked up. (age 5+)

School Age (6-12 years)



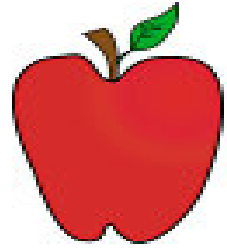
Memory

The repetition of basic concepts by using visual reminders in various key areas throughout the house. For example, when learning the alphabet the letter with pictures were in different places such as on his bedroom door, refrigerator, and family room. (age 6-7)

By using pictures of activities in order of execution-evening routine of brushing teeth, washing hands, going the washroom. This is still on the bathroom wall. (age 6-7)

My son had a hard time recognizing numbers. We counted everything in sight, and also played the card game UNO every night. This helped him recognize numbers, and also when he was slightly older, helped him with math operations as there is a scoring component. We used similar strategies for repetition, for learning the alphabet. (age 6-12)

School Age (6-12 years)



Learning

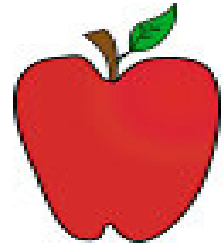
My strategy to get through to the education system (although many teachers and resource teachers knew it too) was to get another psychological educational assessment done by a psychologist who understands FASD. This assessment showed [name of son] real abilities and disabilities and he finally qualified to be placed in a Life Skills program where he understands what is required of him and he is much more comfortable with the learning level. Thank goodness. (age 12)

During grade 2, she was diagnosed as having a short-term memory. She was involved in resource help her whole school career. The resource teacher gave her homework to do at home to repeat things that she learned at school. It was difficult at times, but she has her grade 12 diploma. (age 6+)

Language – Reading Comprehension

Read stories, listen to books on tape, and watch the movie [related to book]. (age 10+)

School Age (6-12 years)



Language – Speaking

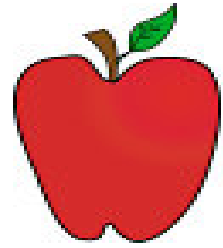
My son was enrolled in speech language/speech therapy classes from 4 years old until he was about 8. I would often do the lessons while driving somewhere. I chose this time because he was held captive by the seatbelt, and we could do small chunks of work - for example, making the “k” sound. I still use the time we are in the car for short, difficult conversations. Since we are not facing each other, it feels more like we are working together than being confrontational. (age 6-9)

Consistently touch base with teachers and administrators. (age 6+)

Understanding Abstract Concepts – Fact vs. Fiction

We constantly talk about every situation (including seen on TV) and ask “is this real? Is this pretend?” School did the same, so now [child’s name] asks the question before we do, and we get him to think it through on his own (he needed lots of practice to get to this point at age 12). (age 8)

School Age (6-12 years)



Understanding Abstract Concepts – Time & Money

Since he understood the length of recess I used this measurement for other time issues. It might be one recess or two recesses etc. (age 7-15)

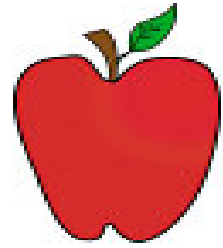
We began using digital clocks, and saying the time as if reading the digital clock. He did not understand expressions like “quarter to four” or “half past six” but understood 3:45 or 6:30. I also asked all his teachers to use the same way of expressing time, so that he did not get confused. He still understands digital time much more than other phrasing. (age 7-16)

Money understanding has come along with the use of it and the need to make change. At first he thought that when he got money back that he was being given money and thought that the change was more than the amount that he had paid. Now he seems to understand that change is less. (age 7-15)

Managing Money

Small steps of responsibility, starting when my son was about 12. I started by having him have an allowance, and made him responsible for buying any candy for himself. Last year, I started also giving him money at the beginning of the school week for lunches. That money was his if he chose not to buy lunches. This year, I have increased his allowance to include lunches and video rentals. I have also had him start two bank accounts with access cards at different banks, so that he can use one account for saving and one for everyday use. (age 12-16)

School Age (6-12 years)



Attention Span

Having him focus on things of interest to him. Gradually increasing the time spent starting at 1 minute and going to 10 minutes. (age 7-9)

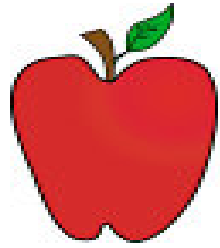
Finding what interests him. Finding ways to do things that are more fun. For example, counting cars to increase his ability to count. (age 7-9)

[We use] medication. (age 7-15)

Focus on one thing at a time and keep it simple. (age 7-15)

Let's say for example, something happens at day care and he's just out of control. So I have to get him talking...and I ask "what's happening for you?". I have to say "No X you're not hearing me. What I want to know, what's happening right now? What's going on right now? What's going on with you? No, no X, what's happening for you right now?" It's bringing him back into focus, really getting him to. That takes a lot of energy just working through with him. It works if you can get him focused, it works great when I do...that. It does take a lot of energy to get him to focus but (I) also walk away with him not being so stressed out. He also walks away feeling okay that he has accomplished something. (age 6+)

School Age (6-12 years)



Fine Motor Skills

Getting him to print using different tools i.e. chalk on a sidewalk, finger paint on paper, a stick in the sand. (age 7)

Sensory Integration

Having the fan of the car on or the window of the car open, even when not weather appropriate. (age 12+)

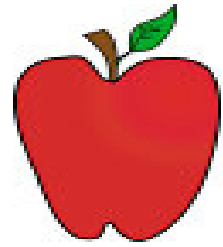
Preservation

We have only recently developed preservation problems. The only thing I have found that can break the hold of some thoughts is to scoop her up in my arms and swing her around till she giggles. At first she is reluctant to let go, but it does not take long to change [her thoughts]. (age 6-12)

Prioritizing

He makes a list and then selects what is most important at the time. Then we will go back to the list and select another item etc. (age 7-15)

School Age (6-12 years)



Self Confidence

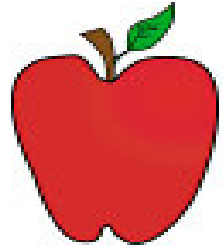
Giving him simple tasks that we know he can be successful at i.e. getting the mail, taking one bag of groceries from the car and onto the porch, putting the table cloth on the table. He likes to use the stove, so with close supervision he makes scrambled eggs. (age 11)

Focus on success and try to state all ideas that need to be carried out in the positive. (age 7-15)

Telling her that others have issues with their bodies. Sometimes hands or legs not strong enough to let someone walk or use hands. Reinforce that all of us are different and it is okay to think differently. Let her know she is doing a great job at thinking things out, doing things. Encourage her to do things she cannot do, giving time to do them and allow her to decide if it is the right time. Remind her of what she does really well, and others cannot do those things. (age 8)

Went to her school and took tactile objects for classmates to hold and close their eyes. Asked classmates to give a word describing what each thing felt like. Asked them who was right. Each child said they were correct, but I explained that they were all right. It is how each of our minds tells our bodies what things feel like, and no one is wrong. They finally understood what a different world our daughter lives in, and began to appreciate it, and became more tolerant of her ways, feelings and how her mind thinks differently. (age 8)

School Age (6-12 years)



Falling Asleep

We have nightmare problems and perseveration in regard to replaying the pictures and actions of past nightmares. The only solution I have found is for her to sleep with me whenever she has been in a stressful situation. That means that on school days she mostly sleeps with me. On weekends things are easier. (age 6)

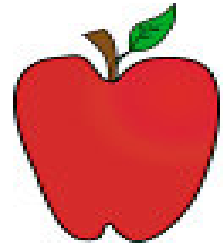
[The] use of medication. (age 7+)

[We use] a routine...i.e. cookie and milk prior to bed time. (age 6-11)

She slept reasonably well, though wakening often. We used a fan on her face even in winter and a heavy blanket even in the summer. (age 12+)

I had a whole evening routine I would do with my son. It started with racing to put on pyjamas, then doing [brushing] teeth together, then reading a story before getting him to lie down. My son loves having his back scratched, so my rules were he had to stay still - mouth shut (no talking), eyes shut, and body still. I would scratch his back for about five minutes, and often found that he was asleep by then. If not, I kept scratching. As he got older, I would scratch his back for a few minutes, then tuck his blankets all around him like a cocoon, before leaving the room. I often had to check as he has never fallen asleep easily. (age 3-10)

School Age (6-12 years)



Sexual Activity

At age 13, started our daughter on the pill, though she wasn't sexually active for several years (to regulate her period and her moods). Once sexually active and at risk for seeing pregnancy as a plan, got her on a IUD as an alternative to having to take pill. (age 13+)

Stealing

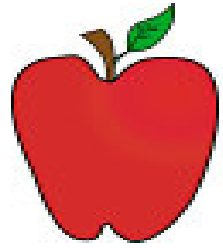
Taught the concrete notion...[that] everything has a home (lives somewhere) and they need to go back or remain there. After a month, this behavior ceased and has not yet recurred. (age 7+)

Removing money from wallets and pockets so he will not steal. After a while he stops checking and then for a while we can keep money in the wallet. Then something triggers him to start checking again and we again remove money from wallet. (age 11)

Confront him. I always know what money is in my wallet so I can with confidence say "You took \$5.00" etc. (age 7-15)

I would mark bills in my wallet, so that I would know what I was dealing with. But we had to take responsibility for making the opportunity available and accept that missing money was our fault. So I locked my purse in the car trunk or wore the strap around my body, once hiding it stopped working. (age 12+)

School Age (6-12 years)



Confabulation

Confront and question carefully, directly and keep it simple. (age 7-15)

When we were dealing with lying, I read a book that encouraged me not to get our daughter to admit her wrong, but to restate my desired expectation i.e. "Don't hit your sister". (age 12)

Alcohol/Drug Use

No alcohol in the house or unopened bottles. (age 10+)



Adolescents (13-17 years)



Language – Reading & Comprehension

Read to her a lot, plus try to buy her books that interest her...[that use] simple wording. (age 13)

Lots of learning issues, so have lots of extra school support – meet with resource people daily to keep up to date with assignments etc. (age 15-16)

Have teen read 'younger' books daily to our 7 year old. Helps with teen's confidence and his improvement of reading skills. (age 15-16)

Learning

Use short sentences and photo (picture) chore lists etc. (age 14)

Understanding Abstract Concepts – Time and Money

Lower or let go of my expectations. Use digital clocks. Repeat, repeat, repeat. (age 14)

Use a countdown clock (timer). (age 13)



Adolescents (13-17 years)



Managing Money

No concept of money management – spends freely and impulsively. So I got a joint account and discuss every purchase to a 'need' vs. 'want'. This has greatly reduced impulse buying. (age 15-16)

Attention Span

Only ask her to do things that take limited time (15 minutes). (age 13)

Making Friends/Keeping Friends

[My daughter] has trouble keeping friends. So I do a lot of reminding her about social graces/rules. (age 14)

Waking from Sleep

I am still experimenting, as my 16 year old son does not believe there is any connection between when he goes to sleep and how easy or difficult it is to wake up. Currently, I am using a vibrating alarm (sold by Canadian Hearing Society), which seems to raise his level of consciousness slightly, and also shaking him slightly while speaking loudly. I try to keep my voice at a normal tone, and do not show frustration. I also will scratch his back or head, as this seems to help. Regular alarms do not have any impact on him - he can sleep through the loudest buzzer for an hour. (age 16)



Adolescents (13-17 years)



Self-confidence & Self-esteem; Impulse Control

For a year, I kept a notebook beside my child's breakfast plate, with two to six non-instructive examples of successes from the previous day. For example, "[Daughter's name] held on to the disk she wanted to throw down the stairs." For difficult days, I often ended up with more examples, from having to think really hard. The notebook persuaded my daughter that I understood and appreciated her struggles. I'd said nothing about it and didn't know if it meant anything to her, but one day when I forgot to make any entries, she said, "What? I didn't do anything good yesterday?" (age 13)

Insist that she try new things as she would not try or do anything. Yet once she does she usually likes it. (age 14)

Sexual Activity

Educate, educate. Use birth control. (age 13)

Confabulation and Stealing

Lots of talk, brainstorming about antecedents of behavior, identifying feelings around the time of the incident i.e. anxiety, past issues that continue to replay. (age 15-16)

Young Adults and Adults (18+ years)



Memory

Keep a calendar on the wall in the kitchen with all appointments or important info. Each day needs a lot of space. He checks the calendar daily. Print notes (i.e. for tasks) with bullets beside each point to check off when it is completed. (age 20)

Remind him a lot! (age 20)

I phone and remind him of appointments, either the day before or the day of. (age 19)

Repetition, repetition, repetition. (age 19)

Reading Comprehension

I pay for [name of son] text messaging on his cell phone and he uses the internet to talk to friends. I always give him spelling or decode words (in syllables) for him immediately when asked, so he doesn't get frustrated and [he] trusts me that I won't make it a teachable moment (that only made him crazy at school). Now he is reading and writing...[and] has learned to spell words and decode many words and is much more receptive to communicating in print. (age 19)

Young Adults and Adults (18+ years)



Living Independently

Trying to develop habits (taking out the garbage every night before bed) in place of the internal motivation that's lacking. (age 18)

Placing the bed and box spring directly on the floor, so items couldn't accumulate underneath (her idea!). (age 18)

Using see-through plastic bins or open hanging storage units, so that she could see her clothes. (age 18)

Buying 'non-break' dishes and other household items. (age 18)

Waking from Sleep

Most times I would call him on his cell phone or in person I would do the following: when I wake him, I explain the reason, "You wanted to go to the movies and it is one hour before you want to go". Then I ask him if he wants me to wake him up again in 5 minutes. The next time I wake him (in 5 minutes), I say, "Five minutes have passed and you wanted to wake up". (age 20)

Young Adults and Adults (18+ years)



Self Confidence and Esteem

We casually speak of FASD often regarding him and others as I am so interested in learning about it. I point out his behavior (days after an incident) and explain how it is typical of FASD or I ask him to explain. I point out his good qualities over and over with great awe. For example, he has an amazing visual memory. I make a big fuss over this skill every time he uses it i.e. finds a lost object. I say how rich we would be if we could find a way to make money from his giftedness. I brag about it to others in front of him. I have overheard him tell others that he is dumb in school but he is really smart at other things like visual memory. (age 17-20)

Managing Money

Letting [my] child know that I was doing the big job of applying for Ontario Disability Support Payments, on condition that I [would] be her trustee...and showing her the complicated forms involved. [Also] arranging for rent to be paid directly from ODSP. (age 18)

ODSP check goes to me; I put it in a joint account. I take out cash for housing. I take out cash for public transit. I transfer money into his account on Fridays for the weekend. I take him grocery shopping. (age 19)

Stressed the complexity of applying for ODSP and made an agreement that in return for my doing so, she would agree to have me as trustee. This was made easier because she'd been in a group home where they were trustee (and I was preferable). (age 18)

Young Adults and Adults (18+ years)



Confabulation

I would prepare him for my question and then I would ask for the truth; then I would leave it for a day or so and ask again; then I would ask if he is lying. Sometimes it would take weeks before he admitted it was a lie. I never gave him reason to think I would get mad. I just wanted the truth. (age 20)

Irritability

I do not get angry but I say, "I will talk to you about this later when you are feeling better". (age 18+)

A preventative strategy: we would avoid setting any precedents for activities we didn't want to have to deal with repeatedly, such as granting a stop at an ice-cream shop, or permission to open the car windows, or to touch the car's instrumentation. (age 18)

In response to an appeal to precedent (i.e. child saying "You let me..."), after which a refusal would produce an outburst, I would say, "That was a mistake". I'd wish I learnt this earlier. (age 16+)

Young Adults and Adults (18+ years)



Getting a Job

I focus on my son's special interests. My son likes food, so I signed him up for a kid's cooking school at a major grocery store. Now he works at a bakery. (age 18)

My son always wanted to be a pilot, so I would take him to the airport to be around planes. His love for the airport has led to him getting a job at the airport. (age 18)