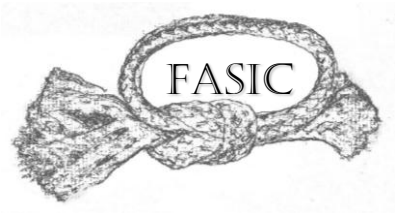
Fetal Alcohol Syndrome Information Centre



Vivien Lourens

My knowledge of Fetal Alcohol Syndrome came from living it.
We were Emergency foster parents for Cape Town Child Welfare for sixteen years.
During that time we cared for many babies affected by alcohol exposure during pregnancy.

But in 1996, one particular little baby arrived who would change our lives.

Her name is Tisha.

We were accustomed to emergency placements. Sometimes we would receive a telephone call
and have only an hour to prepare for a premature or medically fragile baby.
So when Tisha arrived, receiving a tiny premature baby wasn't in itself unusual.
What was unusual was what I was told when she was handed to me. **She was described as a "failure to thrive" baby**, and I was told that she probably wouldn't last the weekend.

But Tisha did last the weekend. And then another.
And slowly our focus changed from whether she would survive to:
How do we help this child live?
That question began a journey
that none of us could have anticipated.
Learning about FAS
Tisha had Fetal Alcohol Syndrome.
A lifelong permanent condition.
100% preventable 100% irreversible

At that time, **finding information about FAS was difficult** enough.

Finding information telling a caregiver what to actually do at home was even harder.

How do you feed this baby?
How do you settle her?
Why is she crying?
Why isn't she gaining weight?
Why does something that worked yesterday suddenly not work today?

Later the questions became:
Why can't she remember something she knew yesterday?
Why does she become overwhelmed by something that seems insignificant to everybody else?
How do we teach her?
How do we prepare her for school? How do we teach her to behave appropriately socially?
And eventually:
How do we prepare her for adulthood?
There wasn't a handbook sitting on my shelf giving me those answers.
So we learned from Tisha.

Development wasn't a straight line

One of the things that became very apparent was how differently Tisha developed.

In the handbook I eventually put together, I included the clinic growth charts of two of my daughters: Leigh-Anne and Tisha.

They were fed the same formula and baby foods, but their development looked completely different.

Tisha hardly gained weight. Every gram was an achievement.

Her milestones were delayed, although intensive physiotherapy made an enormous difference to what she was ultimately able to achieve.

Don't only look at what a child cannot do.

Find out what helps that child do more.

"She won't" versus "she can't"

Probably one of the biggest lessons I learned through raising Tisha was the difference between "She won't do it" and "She can't do it."

That distinction changes the way you respond to a child.

A child with FASD may appear perfectly capable. They may speak well. They may be charming. They may tell you that they understand. And then they do exactly the thing you've just told them not to do.

The natural reaction is: "But I've told you this before!" And yes - you probably have. Many times.

But memory, impulsivity, communication and understanding consequences can all be affected. So repeating something isn't necessarily evidence that your teaching has failed.

Sometimes repetition is the teaching. Repeat, repeat, repeat.

Behaviour is communication
Tisha taught us this lesson very dramatically when she was small. Before she could communicate properly, she used to have terrible tantrums. She would become frustrated and throw herself backwards.
Once she learned to speak, those tantrums reduced considerably.

The behaviour wasn't simply "naughtiness."
She was trying to communicate something and didn't have the ability to do it another way.

Instead of only asking, "How do I stop this?" we learned to also ask:
What is Tisha trying to tell us?

What is Tisha trying to tell us?
Is she hungry? Is she tired?
Is there too much noise?
Is something unfamiliar?
Does she understand what is happening next?
Is she frustrated because she can't find the words?

Sometimes we never discovered the reason.
But looking for the reason rather than simply
punishing the behaviour made an enormous difference.

Structure became our friend

Another major lesson was the importance of predictability. Changes can be extremely difficult.

If we were going somewhere unfamiliar, we learned to explain where we were going and what was going to happen.

At home, routines helped. At school, routines helped.

Simple instructions helped.

Visual reminders helped. Preparing her for transitions helped. And consistency helped.

The handbook eventually became filled with very ordinary suggestions - picture calendars, checklists, start-and-finish boxes, short activities and advance warnings.

When a child struggles to organise information internally, providing that organization externally can change the entire situation.

School taught us another lesson

Our experiences with education were varied. Interestingly, some of Tisha's most positive early experiences were in ordinary playschool and pre-primary environments where teachers accepted her and made allowances when she couldn't do what the other children could do.

She loved school. She is a very social person. But academic learning was difficult.

Reading, numbers and particularly abstract concepts such as money and time were challenging. At one point I wrote that when Tisha went shopping, everything cost R5.00.

Yesterday and tomorrow could mean almost anything.
That forced us to reconsider what successful education actually meant for her.
Was success simply moving through grades? Or was success helping Tisha eventually function as safely and independently as possible in the world?
Reading and mathematics matter. But so do personal hygiene, money, transport, communication, relationships, workplace behaviour, safety, and knowing when to ask for help.
We have to educate the future adult, not only the child sitting in front of us today.

Teachers and parents need one another

Another lesson I would like to emphasise is the relationship between caregivers and professionals.

Parents and caregivers can sometimes feel intimidated when speaking to teachers, therapists and doctors.

But the caregiver knows that child in a way nobody else does.

At the same time, teachers and therapists may see things that we don't see at home.

It should never be: "I know better than you."

It needs to become: What do we know between us?

In the handbook I wrote that "I" must give way to "we."

No single person can meet every need of a child with FASD.

The best results we saw came when caregivers, teachers, therapists and medical professionals actually listened to one another and shared information.
I was lucky to find marvelous professionals at all the clinics at Red Cross Hospital who helped me so much.

Don't do everything for them

There is another temptation caregivers face. Sometimes it is simply easier to do something for the child. You can put the jersey on faster. You can pack the bag. You can find the shoes. You can complete the task.

But if we always do that, we remove the opportunity to learn independence. With Tisha, we learned to let her try. And try again. But also to recognise when frustration was becoming too much and stop before the situation became a disaster. And then try again tomorrow.

Sometimes she would learn something beautifully and the next day appear to have forgotten it completely. I used to call that "Tisha unplugged." And then, strangely, something we thought was completely forgotten could reappear months or even years later.

Living with Tisha taught us that development isn't always a neat upward line.

Look for the person, not only the disability

Perhaps the most important thing I can say is that FAS is part of Tisha.

But FAS is not Tisha.

Tisha was an incredibly loving little girl. She was social. She loved people. She had strengths, preferences, humour and abilities that were entirely her own.

Our job wasn't to spend her entire childhood reminding her of everything she couldn't do. It was to find what she could do and build from there.

Self-esteem matters enormously. A child who spends every day being corrected, failing and being told what they have done wrong eventually begins to believe that they themselves are wrong.

We tried to praise success, recognise effort and give Tisha responsibilities that allowed her to contribute.

Every child needs to feel**: I am useful. I belong here. I have something to offer**.

What I would tell caregivers today

If I could sit down with a caregiver who has just learned that their child has FASD, I wouldn’t pretend that the journey will always be easy.

There will be frustration.
There will be repetition.
There will be days when you are absolutely certain something has finally been learned - only to discover tomorrow that you're starting again.

Learn your child. Don't only learn the diagnosis.

Find out what overwhelms them. Find out what calms them.
Find out how they learn. Find out what they're good at.

Create structure around the things they cannot yet manage for themselves.
Teach skills concretely.

Prepare them for change. Celebrate progress that other people might consider tiny. And don't be afraid to advocate for them.

Most importantly, don't allow a diagnosis to become the limit of what you imagine for that child.

The handbook I eventually wrote was never intended to be a medical textbook.

It came from something much simpler:
I needed practical help, and I couldn't find it.
So I began writing down what we had learned in the hope that another caregiver might find something in our experience that made their own journey a little easier.

And after all these years, I think Tisha herself taught us the most important lesson:

Change your expectations where you need to - but don't stop expecting possibilities.

Tisha – the young lady

Tisha is now 30, reading and writing is still a struggle, but her personality remains the same.
She had a fulltime job until Covid hit and she was laid off.
She was eventually re-employed for one day a week and loves the work – sticking bar codes on products.
WhatsApp on her phone and tablet play a big part in her life, chatting to her friends.
We do have to monitor her as sometimes she signs up subscriptions without realizing or joins groups where she doesn't know anyone.

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