

Snapshots

A family perspective of living with fragile X

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Stages of parenting

- Pre-diagnosis
- Diagnosis
- Post-diagnosis
 - Disability expert
 - Ben and James expert
 - Focus on the future

Pre-diagnosis

- James' sleep pattern was horrible. Chris and I were normally getting just three hours sleep a night. James was constantly demanding and often cried or hit out for no reason. Sleep deprived, spending the day cleaning up poo and vomit, and trying to cope with James' difficult behaviour, I knew our family needed help but I didn't know where to start."



Pre diagnosis - Denial

- “I thought that Ben would be fine by the time he was five and James must be OK because who has more than one child with a disability”
- Denial was a coping strategy
- We did not understand our children so we did not know how to meet their physical, emotional or developmental needs
- Poor access to services



Support Services

- We needed:
 - Access to services
 - Carer support
 - Help with meeting our children's most basic needs
 - Eating
 - Sleeping
 - Emotional regulation
 - Communication
 - To develop an understanding of our children
 - Contact with other families

Diagnosis

- “I felt like I had been hit by a train – it was a physical pain that lasted months”
- “I saw our children with different eyes – they were different from other kids, they had a disability that would affect them their whole lives and there wasn’t anything I could do to make fragile X go away”
- I lost my sense of hope and expectations for my children



Diagnosis

- Hope
 - “They might have fragile X Anita but they are still two beautiful boys”
 - Positive observations
- Gentle reality
 - “They are likely to need help balancing a cheque book as adults”
- Understanding
 - Of how stressed we were
 - Grief counselling
 - Contact with other parents



Post-diagnosis – disability expert

- I became an expert on what the boys couldn't do
- My understanding of the boys' difficulties was beginning
- I felt overwhelmed by their needs
- I became very focused on providing the boys with the perfect environment – everything we did was therapy
- I wanted an expert who would have all of the answers and provide the perfect therapy
- I was careful not to hope or have expectations. I focused on getting through the days or weeks ahead



Disability expert

- We needed:
 - Information on those parts of fragile X that affected our children
 - Sensory integration, dyspraxia, autism, hyperarousal...
 - Strategies to achieve everyday activities
 - Information about what our children were achieving
 - Learning about our children's strengths

Becoming a Ben and James expert

- I became aware of Ben and James's strengths and abilities
- I learnt specific strategies that work with Ben and James
- I gained the confidence to do stuff with the kids
- I rediscovered my sense of hope and had expectations of what the boys will achieve
- I avoid saying they can't do it



Expectations

- The kids can do it if we give them enough support
- I set specific goals for the kids
 - James will be able to go supermarket shopping with me
 - Ben will learn to catch public transport to school
 - We will have an enjoyable family holiday
- We get the kids out and doing stuff

Strategies for every day stuff

- Motivator
 - Special interest or extrinsic reward
 - Celebrate success
- Predictor
 - Visuals
 - Social stories
 - Rehearse
 - Structure or routine
- Regulation strategy
 - Plan transitions
 - Calming strategies
 - Prediction strategies
- Reduce the task to what is doable



Looking at the future

- My goal is to support the boys to be happy and fulfilled adults
 - independent as possible
 - understood by others
 - enjoy every day
- This is a team effort
- Expectations + strategies = success



Summary

- We need to have hope and expectations for our kids to succeed
- We need to be brave like our kids and get our children involved and independent
- We need to become experts on our children and ourselves
- We do not have to do this by ourselves