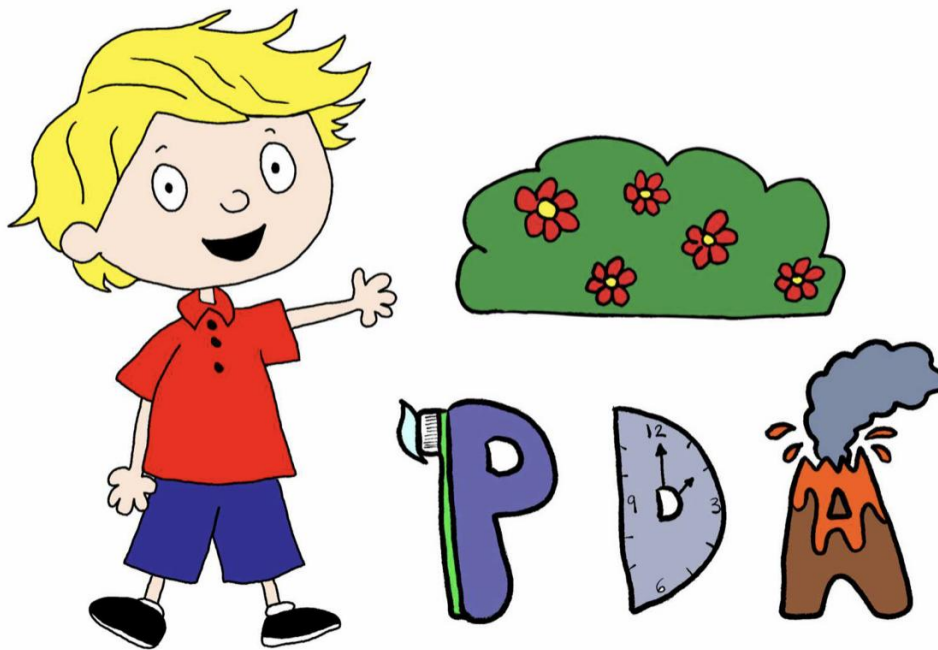


Understanding PDA: For Kids & Grown Ups



Written by: Stacey Freeman, Max Freeman & Jay Freeman
Illustrations by: Stacey Freeman, Max Freeman & Jay Freeman



Dedication

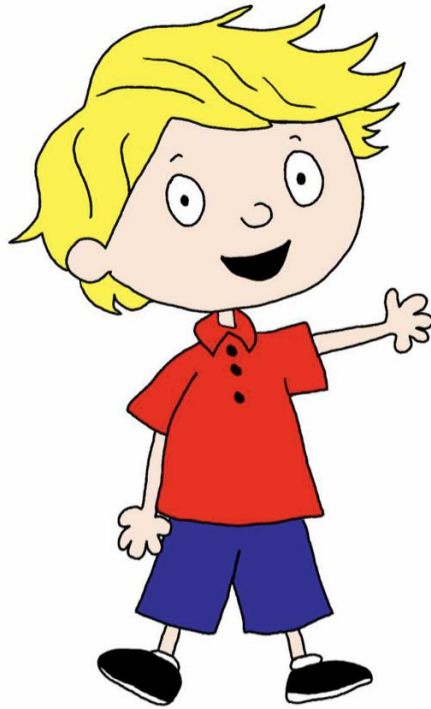
This book is dedicated to The PDA Society.

Thank you for the work you do to support families like ours, and for educating others about PDA.

We would also like to dedicate this book to every PDAer and their families.

We see you.

From the Freeman family.



My name is Ethan, and I have been diagnosed with something called Pathological Demand Avoidance (PDA), which is a profile of autism.

HURRY UP

GET DRESSED

I'M HUNGRY

I NEED A WEE

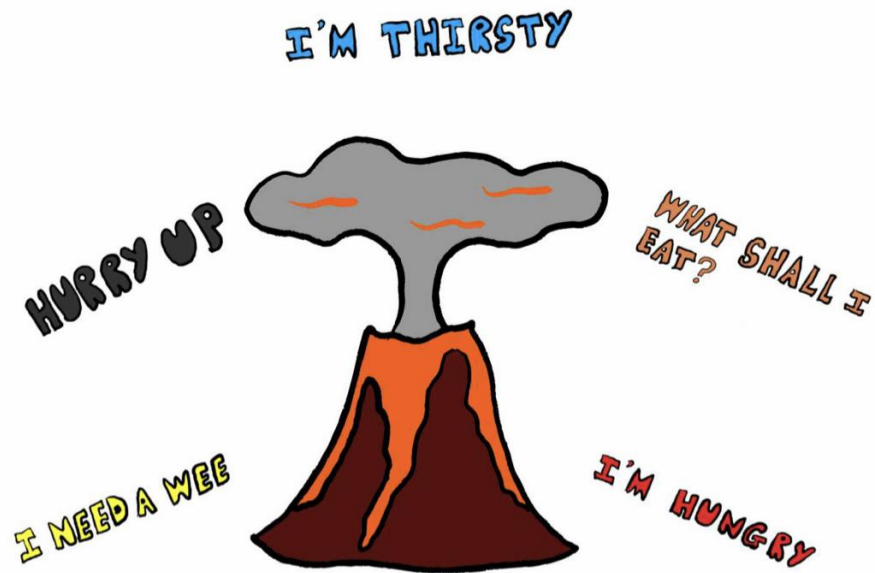
I'M THIRSTY

**PDA can make it hard for me to handle certain things,
like demands or expectations.**

~~WON'T~~
I CAN'T

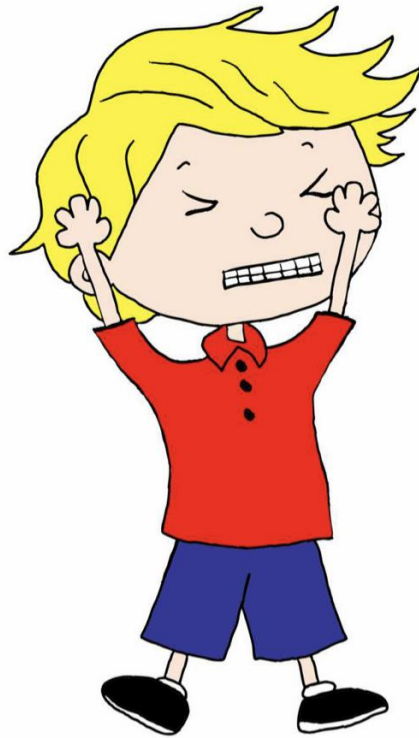
Lots of people don't like doing things at times, but when I'm faced with a demand...even something I want to do...sometimes I just can't do it.

It's hard to explain. But I'm going to try.



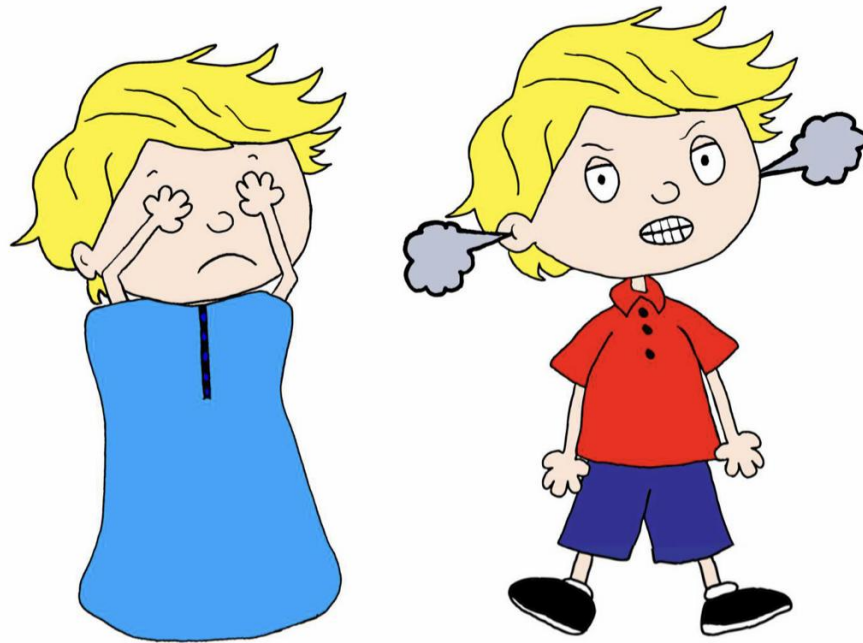
When people ask me to do things, or expect things from me, I get a horrible feeling inside...like pressure building in a volcano.

It can even happen when I expect things from myself!

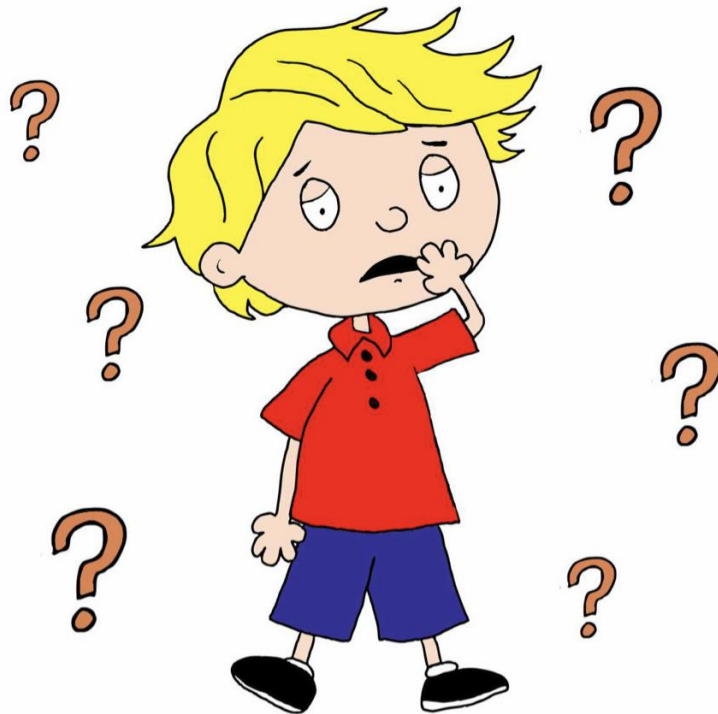


Sometimes, I feel like something bad is going to happen, and I begin to panic.

If I don't feel safe, or like I'm not in control, I can become very stressed, very quickly.

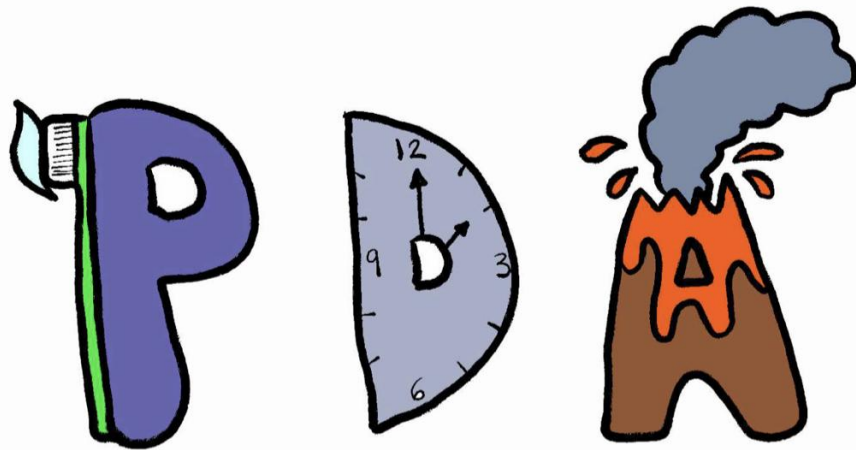


I don't want to disappoint people, but when I am anxious...I can completely shut down, or explode.

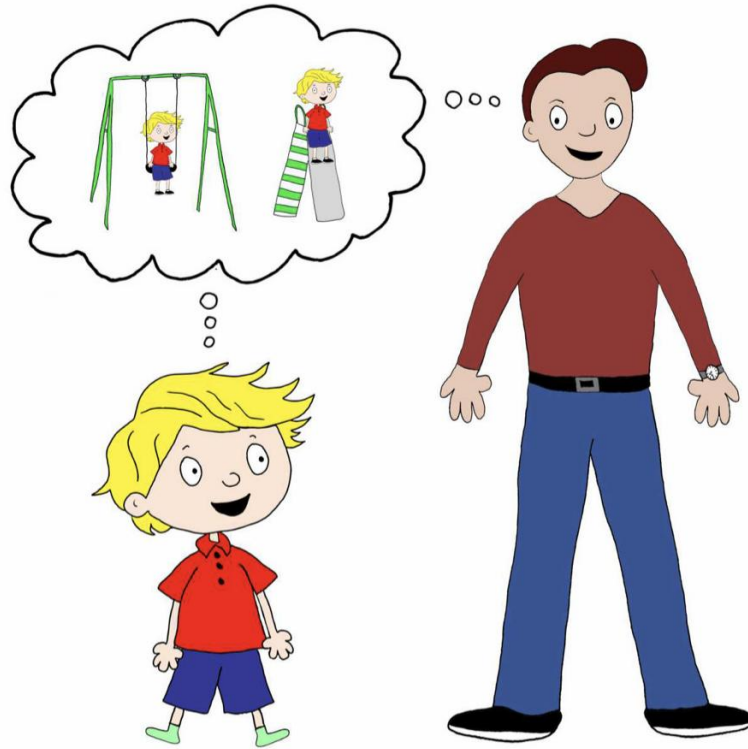


**My body seems to react to things very strongly, which
can be confusing.**

**Especially when it's over things that don't seem to
bother other people.**

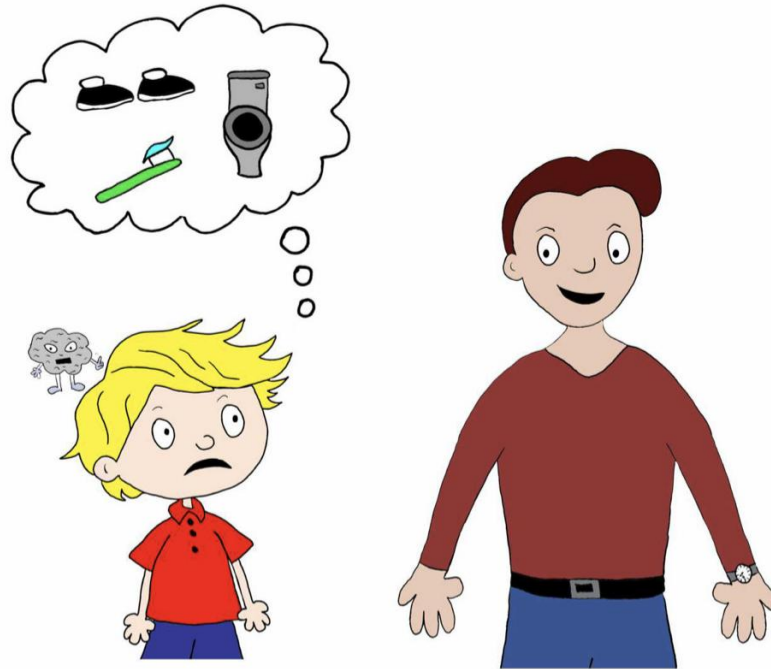


Let me give you an example.



One day, my uncle asked if I would like to go to the park.

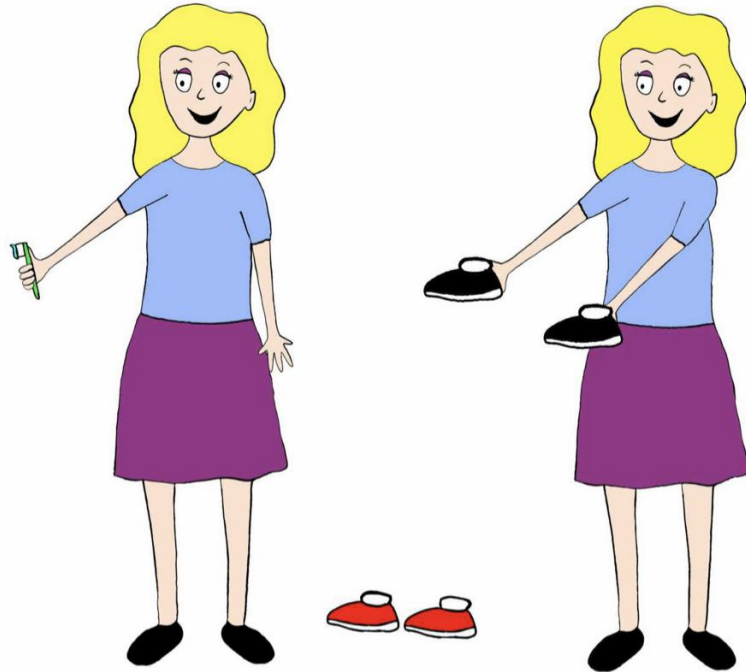
I really wanted to go, but I knew that to get ready for this, I would have to clean my teeth, go to the toilet, put on my shoes and coat, then walk to the park.



Suddenly, I began to panic, and my body became tense.

It was like my brain was frozen, and I couldn't breathe.

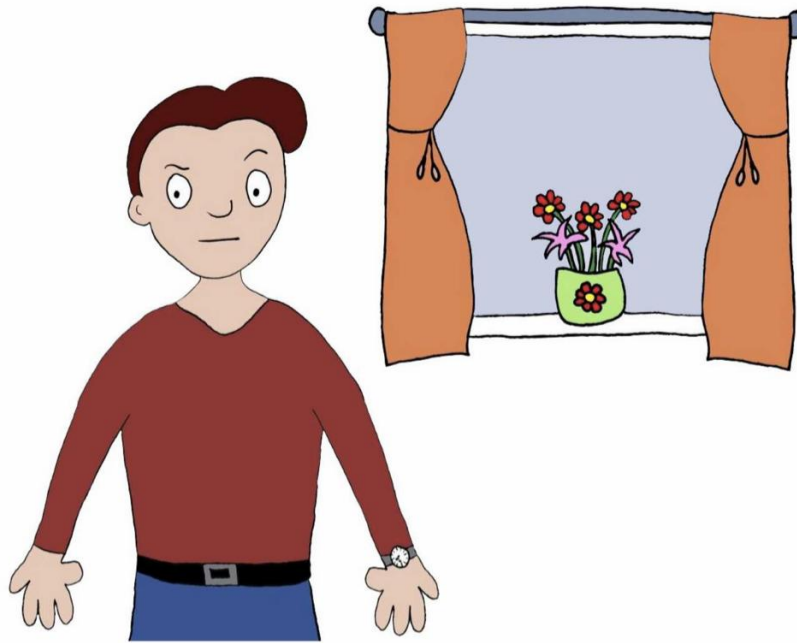
My uncle stared at me, expecting an answer. I opened my mouth to speak, but nothing came out.



My mum could see I needed help, so without saying a word, she fetched my toothbrush, and let me clean my teeth downstairs.

She then helped me put on my shoes, letting me choose which ones I wanted to wear.

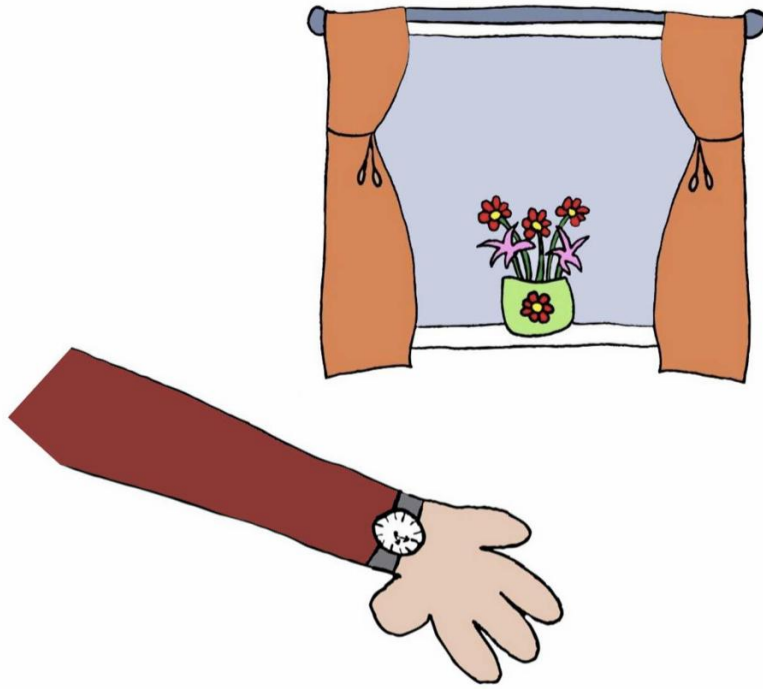
I could breathe again.



My uncle kept saying that I was big enough to do these things by myself, and that made me feel bad.

I was so embarrassed, as I knew he thought I was being lazy.

But the truth is, without my mum helping me, there was no way I could have gotten ready. My brain wouldn't let me.

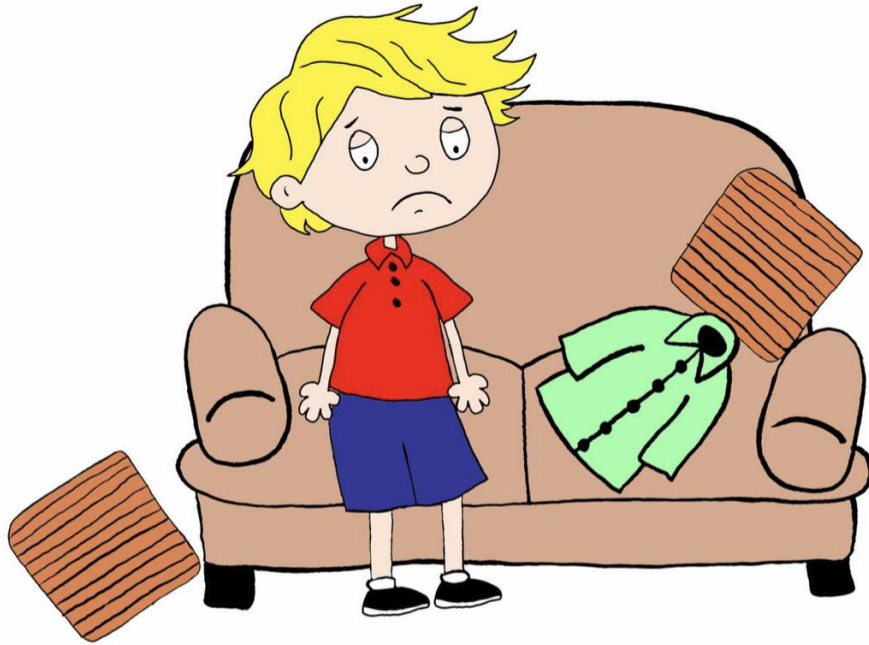


Every time my uncle looked at his watch, a horrible feeling washed over me. I could feel his impatience.

My stomach felt tight, and a lump seemed to form in my throat.

I thought I was going to be sick.

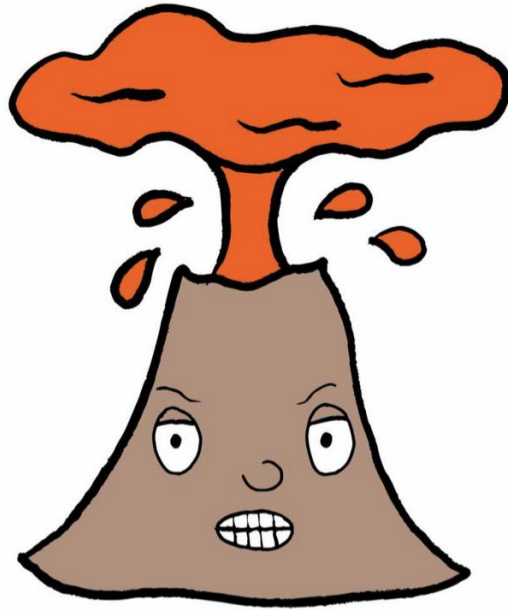




Mum placed my coat on the couch, close to where I was sitting.

I was about to reach for it when my uncle said, “Come on now, hurry up and get your coat on! We need to get going!”



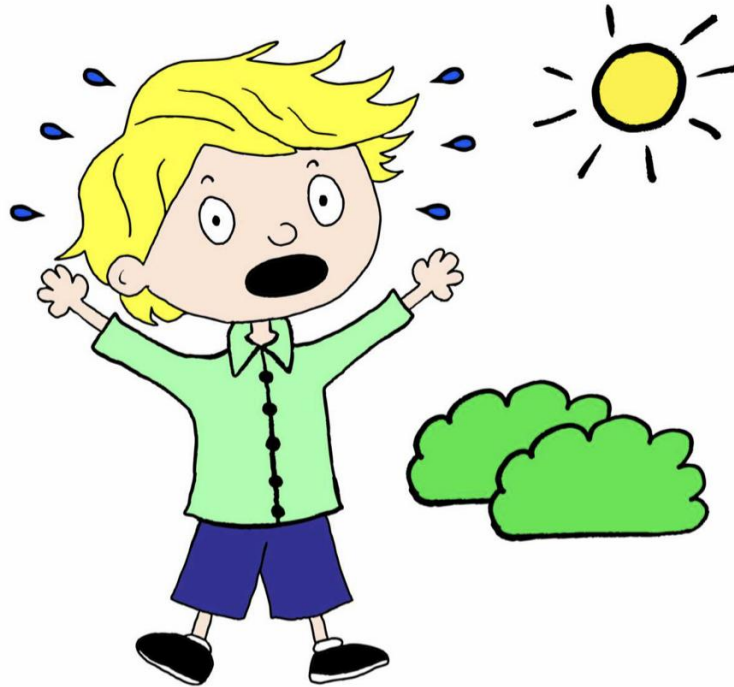


I could feel myself bubbling, so I tried to push the feeling down.

I held the coat in my hands, but something stopped me from putting it on.

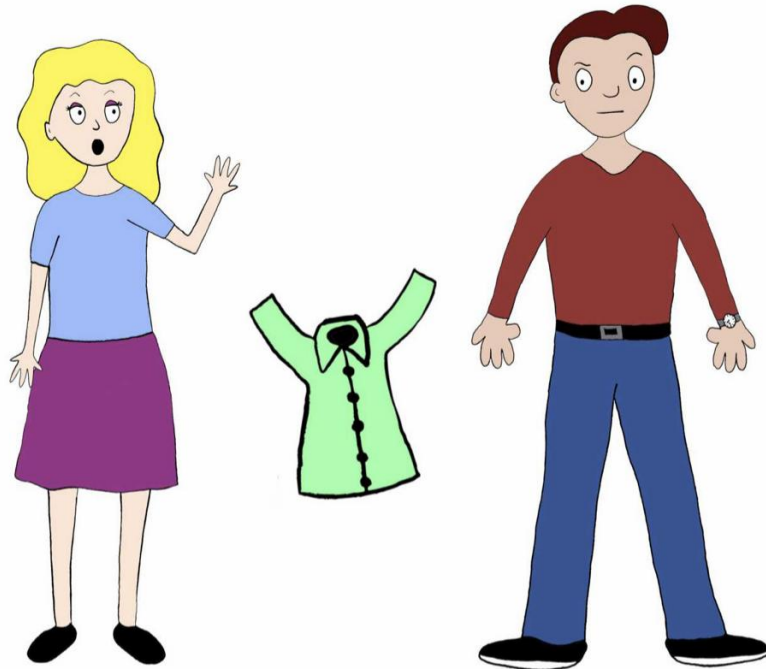
"I don't think I need a coat." I announced.





My uncle looked annoyed. "Oh for goodness sake, Ethan. Just put your coat on. Why are you making this so hard?"

"I'm not!" I replied. "It's just that I'll be so warm from running around, I don't think I'll need one."



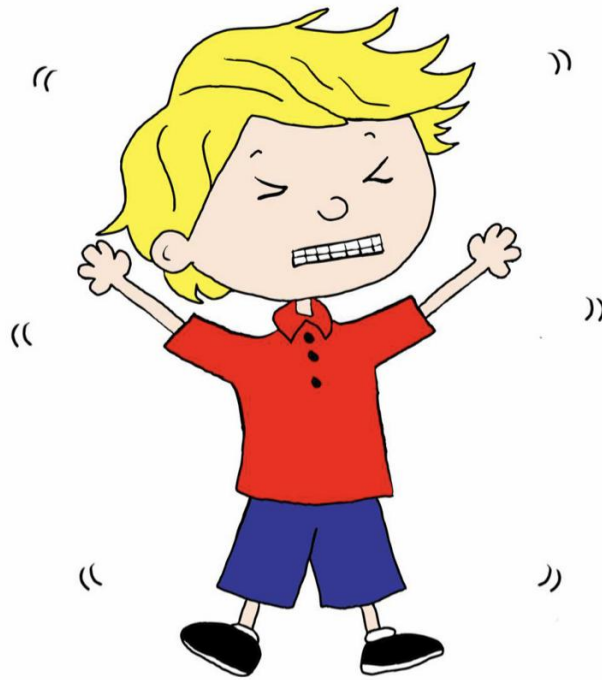
Mum tried to help.

"Why don't you just take the coat with you in case you need it later, but don't wear it right away?"

I was happy with that...but my uncle wasn't.

"No coat, no park!" he declared.

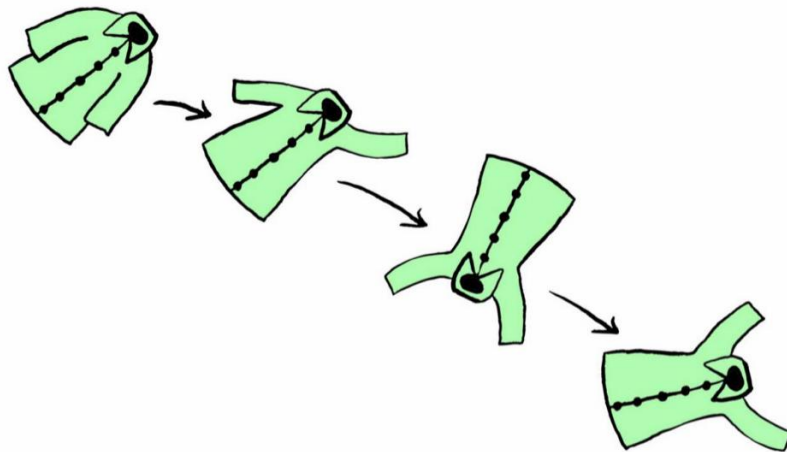




I tried to hold my feelings in...but I couldn't.

My face scrunched up and my body began to shake.

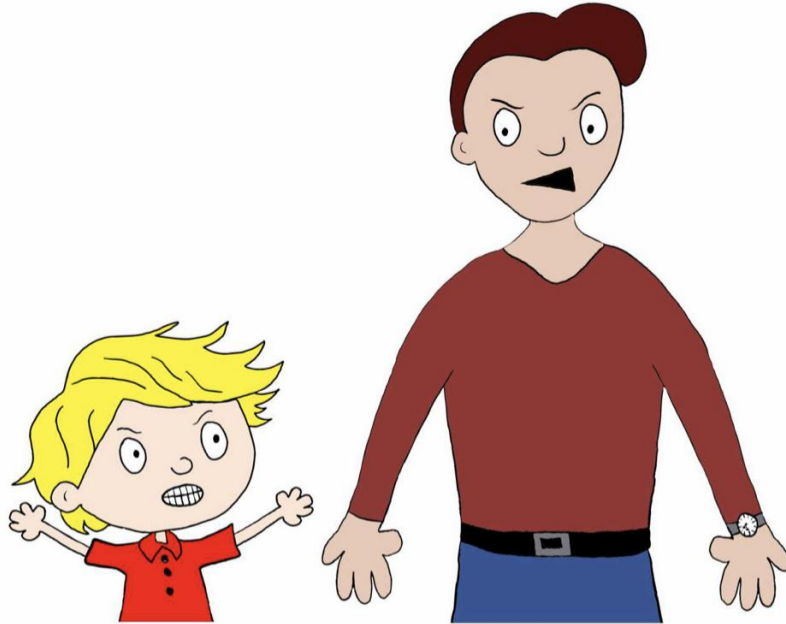




I don't know why being told to do something makes me feel like this, but there was no way I could put that coat on. Not now.

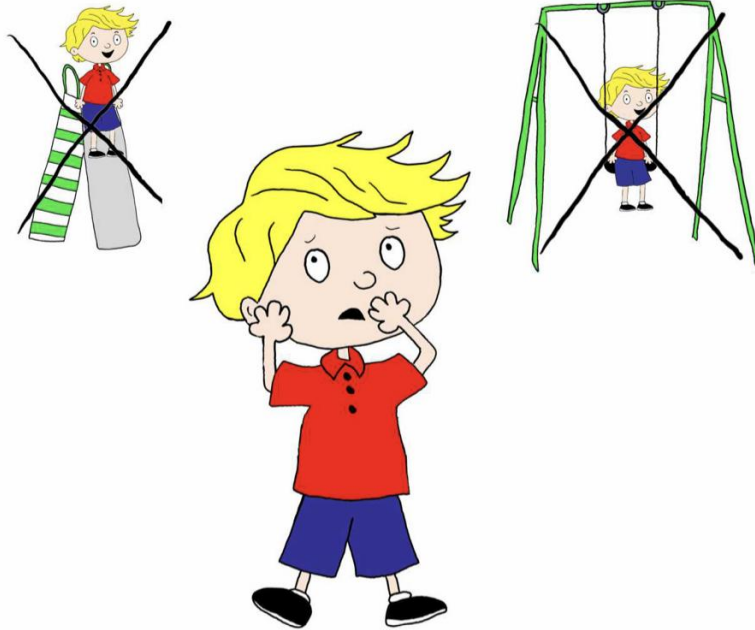
I grabbed my coat and threw it across the room.





My uncle commanded, "If you don't pick up your coat and put it on, I will not take you to the park."





I felt helpless and trapped.

Why should I have to wear my coat just because he said I should?

Without thinking, I reacted by screeching, “I AM going to the park, and you ARE going to take me!”

AUTONOMY



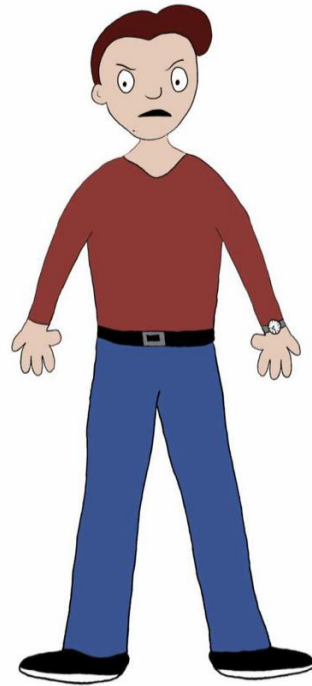
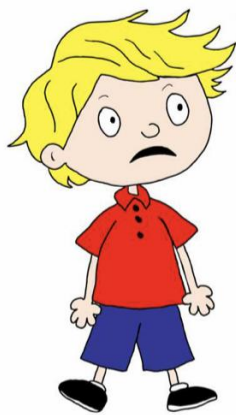
CHOICES

Although I knew that he wouldn't really take me, I needed to feel like I had a choice in the matter.

It was as though by saying this to him, I felt less powerless, in a situation where I was not in control of anything, including myself.



BAD



My uncle yelled, "You are the most ungrateful, rude child I have ever met. I regret offering to take you out, and rest assured I will never do that again!"

I felt crushed.

I kept thinking about what a bad person I was, and how nobody liked me.





**A part of me wanted to sob and hug my uncle, but
another part of my brain took over.**

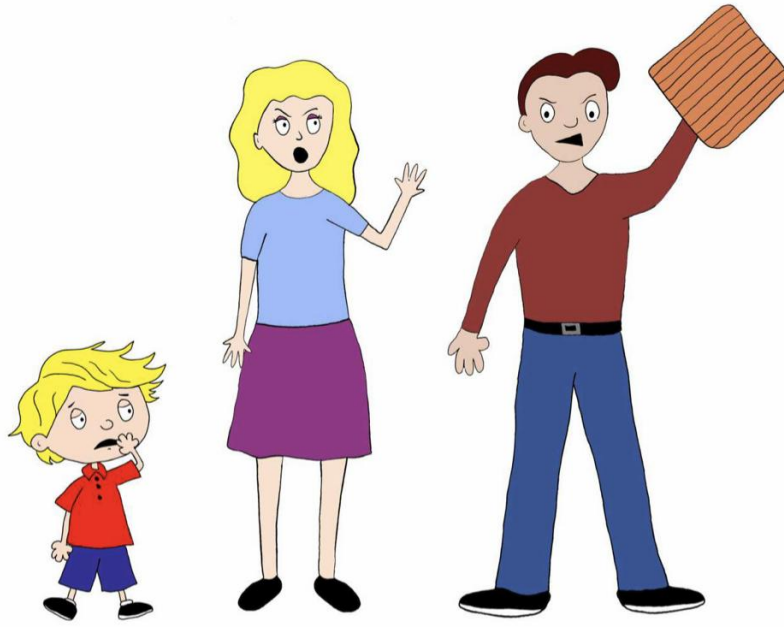
**So instead, I picked up a cushion and launched it in his
direction.**



As the cushion made impact, my uncle became extremely angry.

I was scared and confused, and didn't know how to react. I smiled nervously, anxious about what was going to happen next.

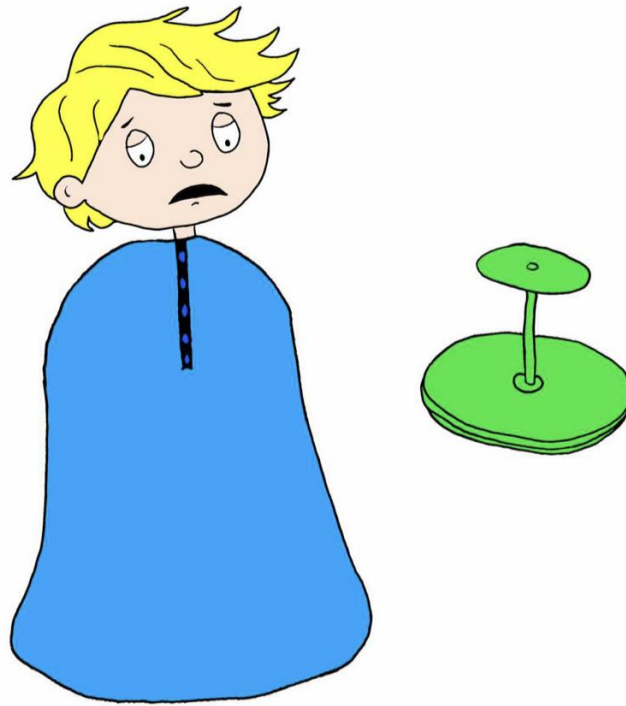
This only escalated my uncle further, and he picked up the cushion, aiming it at me.



My mum tried to explain that I couldn't help it, and that the demands had become too much for me to handle.

But my uncle wouldn't listen.

Mum wedged herself between us and asked my uncle to leave.



It took me a long time to calm down, and there were so many emotions, I couldn't process them.

But once I was calm, I felt so ashamed.



I understood that my uncle was trying to do a kind thing, but as my mum had tried to explain, the build up of demands made me feel threatened and so out of control, that I couldn't take any more.



**ICAN'T GO TO
BED!
BATMAN
FIGHTS
CRIME AT
NIGHT!**

Although this is one way I can react to demands, I don't always explode like this.

Sometimes, if I find demands too much, I will make excuses so I don't have to complete them. Or I will find ways to delay completing them.



For example, when I needed to get ready for an appointment once, I created a character and a language that only I could understand.

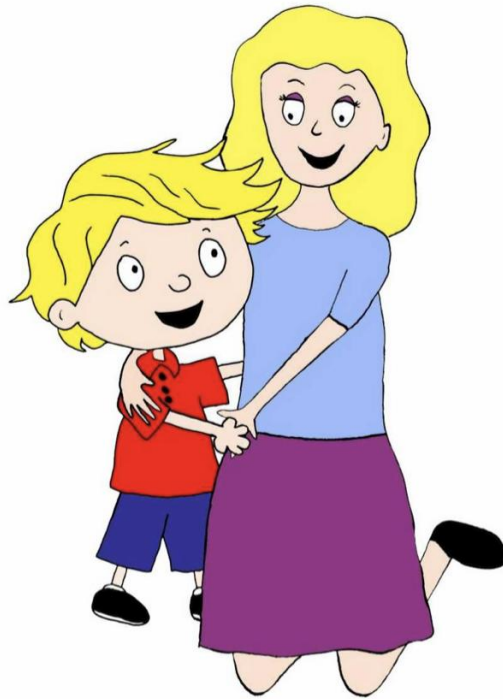
It was difficult for anyone to ask me to do anything, because my character couldn't speak English.



And sometimes, I will pretend to be a character to make demands easier to follow.

For example, I might have been able to get ready for the park if I had been a police officer that was getting ready to go on patrol.



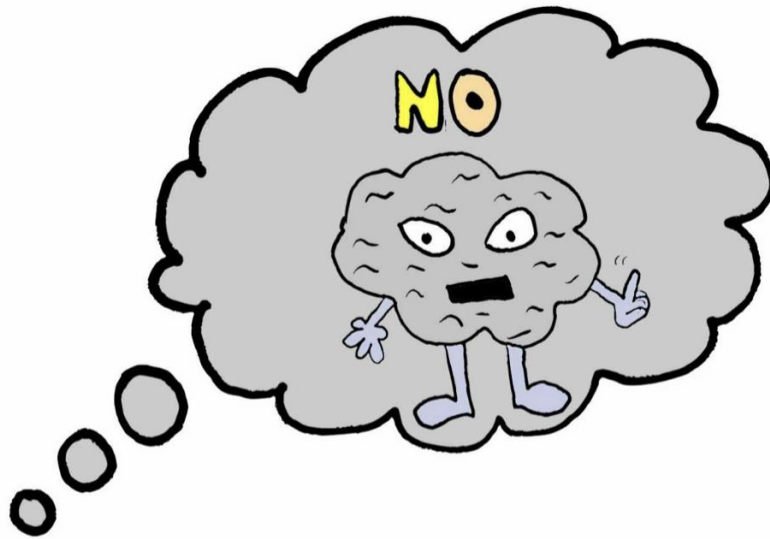


After the incident, we reflected that if the park visit hadn't been arranged so last minute, if I hadn't been rushed, and if my uncle hadn't made comments or been impatient with me... I might have coped a little better.

But for some reason, a lot of grown ups struggle to understand this, and think that because I am a child, I should just learn to do as I'm told.

They don't consider my feelings or how hard things are for me.

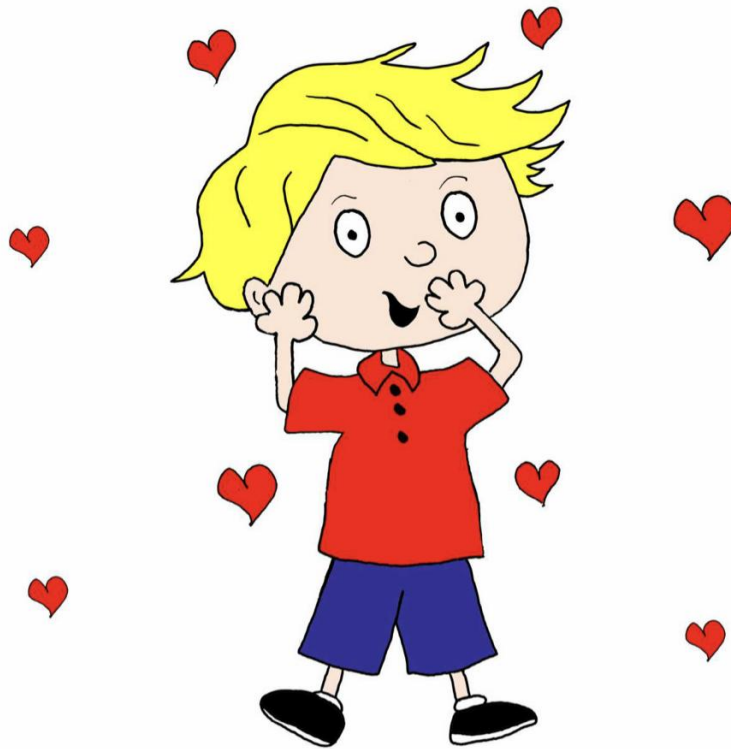




Sadly, I can't control how I respond to demands because how I feel varies from day to day, or even moment to moment.

I know that can be hard for other people, but it also makes me feel anxious.

PDA can be difficult to comprehend, but it means such a lot when people try to understand.



Something I would like people to know is that I am a nice person with a kind heart.

I just need a little more help than other children to cope with everyday demands.

So here are a few things that people can do to help PDAers like me.

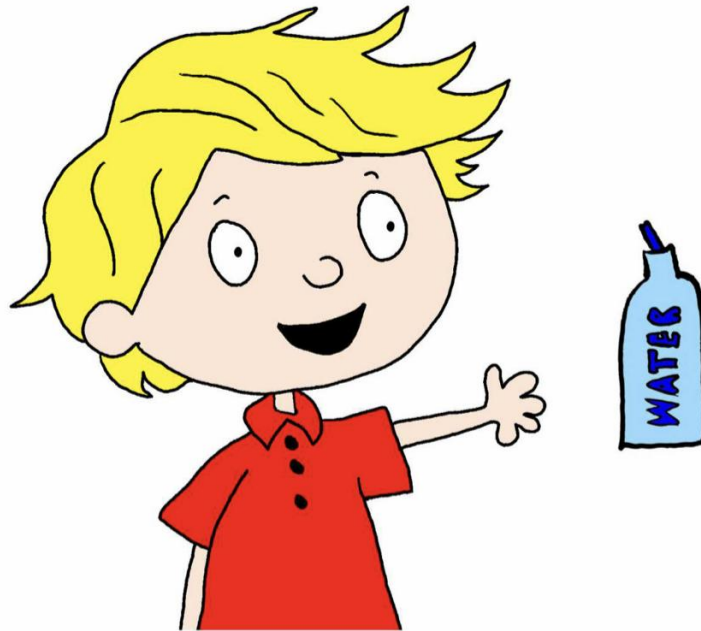


CHOICES



I feel like I can cope better when people are patient and speak to me in a calm voice.

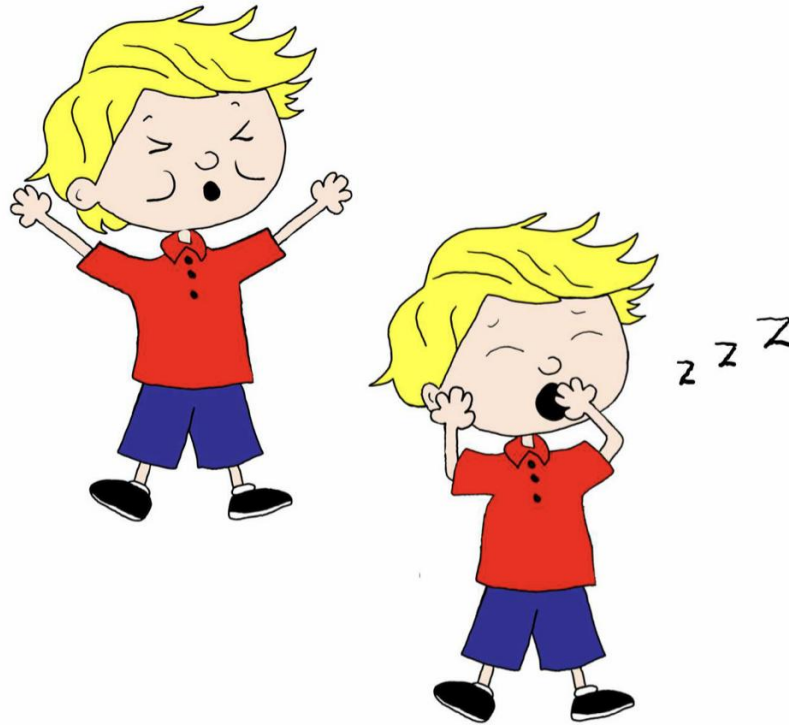
It is helpful when people are mindful about the language they use, and when they give me choices so I feel as though I have some control over what happens.



For example, if my mum wants me to drink water, rather than instruct or tell me to drink, she might place a bottle near me, or suggest that we have a drink together.

It makes it feel like less of an order or demand.

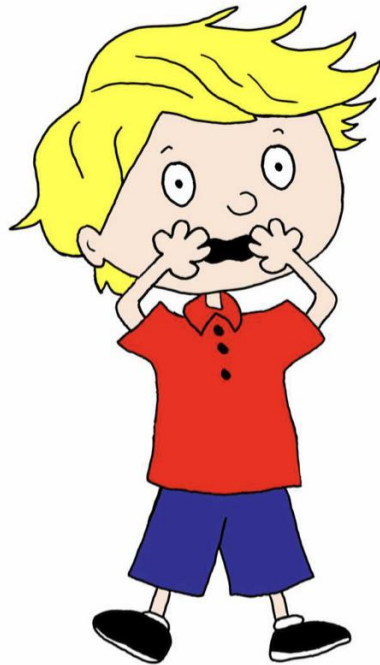




Sometimes, I try so hard to hold everything inside because I'm scared that people won't like me if I'm myself.

But this makes me very tired, and can actually make things worse when I can't hold it in any longer.





~~CHOICES~~

I just
can't

I know some people think I am trying to be difficult, and feel that I don't deserve 'special treatment', but it is important for people to understand that how I react really isn't a choice.

If I could handle demands like other kids, my life would be so much easier, and people wouldn't be annoyed with me all the time.





I really wish that more people recognised and understood PDA, so that those of us with this profile of autism could feel happier and more supported in the world around us.

I want to thank you for reading this book, and hope it has helped you understand PDA a little better.





And just one final note from me...

So many times, I have heard people say that if somebody has not been 'diagnosed' with PDA, then PDA helpful approaches should not be used.

If you suspect somebody meets this profile of autism, please go to The PDA Society website and look through their resources. Or better still, attend their training.

Without support, we will continue to struggle. With your help, we can thrive.

So please, get to know us as individuals, and help us based on our needs rather than a diagnosis.

Did you know?

Many PDAers do not respond to approaches typically recommended for autistic people. (And in fact, every autistic person is an individual, so there is no 'one size fits all' approach for autistic people anyway!)

For example, while structure and visual supports can be helpful at times... they will not always be effective and can actually cause anxiety.

Sometimes, I like being given a visual timetable, so I know what is coming next. However, at other times, it can make me feel overwhelmed.

Visual timetables can trigger my threat response, and make me feel as though I have little control over my day and the things I am expected to do.

It can help to have a loose structure in place, and give me options to choose from...but if anything becomes too rigid and routine, my demand avoidance will likely be activated.

So it is really important for anybody working with a PDAer to learn about PDA and provide tailored support.
