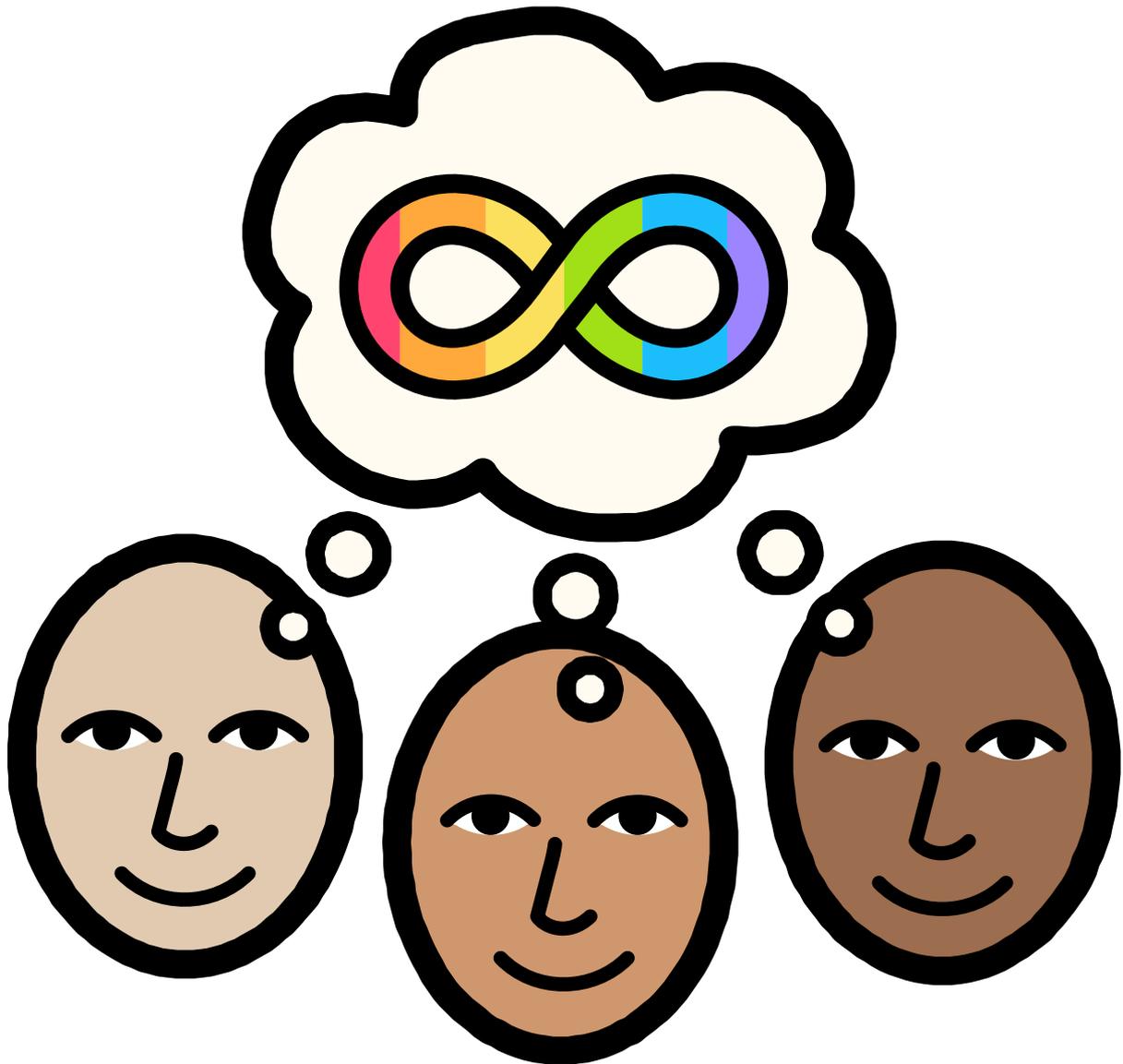


# Parent and Carer Support

Information for Parents of Autistic Children





The links, adverts and 'words of wisdom' in this pack have all been contributed by parents and carers of autistic people.

Rebecca, one of our Education Specialists and an autism specialist teacher, collated the responses given from across various forums.

If you would like any further support, feel free to contact her at:  
[rebecca@widgit.com](mailto:rebecca@widgit.com)

Thank you to all of the people who contributed.

Widgit is not affiliated to any of the companies or individuals and advises that you use this as a guide to research and make your own decisions about what is best for your family.



This is part of our Autism Acceptance Week Support pack. Other resources include

- toileting communication cards
- regulation scales
- social stories

Download for FREE at [www.widgit.com](http://www.widgit.com)

Full pack with over 150 resources to be released in June.



James is a dad to two boys, Jude and Tommy who are both autistic. On his social media he shares stories about their everyday life and hopes that his stories support other carers as well as helping him to be the best dad that he can be.

Thank you to James and his followers who contributed some comments.

**Instagram:** [@storiesaboutautism](#)

**Facebook:** [www.facebook.com/storiesaboutautism](http://www.facebook.com/storiesaboutautism)

**Website:** [www.storiesaboutautism.com](http://www.storiesaboutautism.com)

What advice would you give to parents of a child who has just received an autism diagnosis?

—Stories—  
AB UT  
AUTISM

*'However you feel right now is ok. It's ok to be angry, relieved, scared, happy, frustrated, anxious, alone. Your feelings will change and develop over time. If they're very raw right now that's ok, things will get better.*

*Look to others for support. Find your tribe, make new friends, even if it's just online, but find other people who get and understand your life. Learn from other families, notice similarities, but don't waste time comparing.*

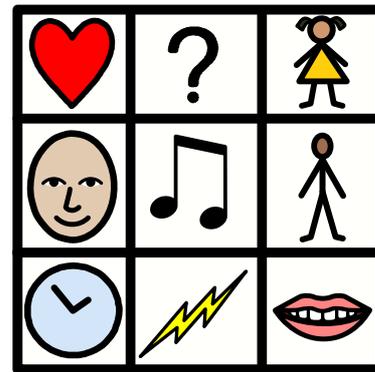
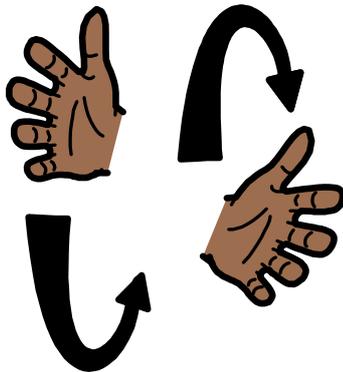
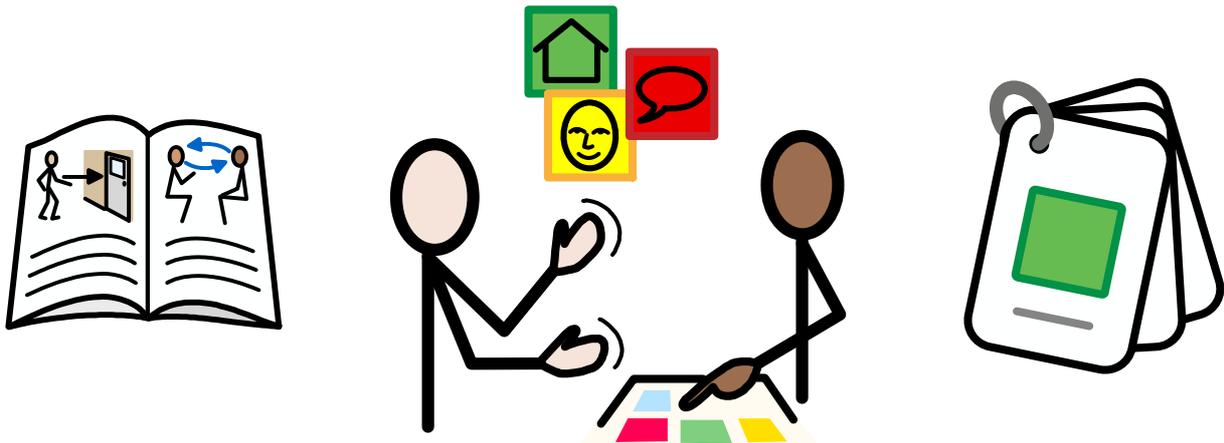
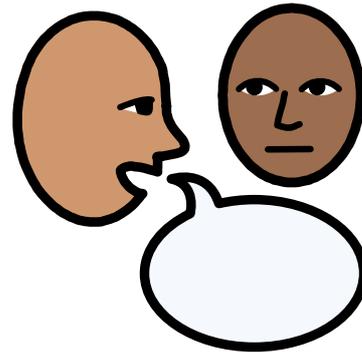
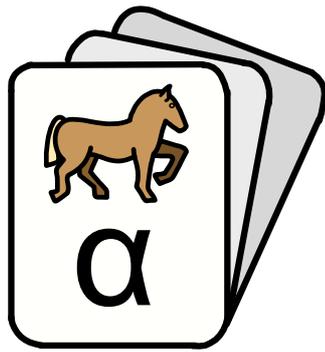
*Nobody knows what the future holds for any of us, and everybody, I mean EVERYBODY on the spectrum or not, is different and unique.*

*Just because your child hasn't done something by the age of 5, it doesn't mean they never will. I've known autistic adults say their first words in their 20's. Never give up.*

*Read about, watch, and listen to other families and to autistic adults, but most of all learn what works from your child.*

*Join them in what they enjoy, flap with them, bounce with them, make their special interests your special interests. Develop that bond between you, they will be your greatest teacher.*

*Finally, breathe. Make time for you. We can become so caught up in our kids, wondering about the best therapies, fighting for their needs, that we neglect ourselves. You need to be happy and healthy too. If you are, you'll be in a much stronger place to be the parent that they need.' James*



*'I had no information when my son first started using PECS so was clueless. I'm confident in what I'm doing now but there should be more information on non verbal methods to help give everyone a method of communication.*

*Find out what different methods to use and research where to find them. You can use Widgit. Get info on grants available to help towards funding. Ensure that parents and school use the same symbols and that if they feel symbols aren't working to use real photos of the objects instead. Try all ways that work for your child.*

## WELCOME TO HOLLAND

by Emily Perl Kingsley



I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go.

Several hours later, the plane lands. The stewardess comes in and says, "*Welcome to Holland.*"

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "*Yes, that's where I was supposed to go. That's what I had planned.*"

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.



**Cannock Chase  
Autism Support Group**

Parent Support Group on Facebook

# Children's Choice therapy service ltd

*'Highly recommended Children's Choice Therapy Service.  
Alison Hart has been amazing for us.'*

11D Lancaster Park, Needwood, Staffordshire DE13 9PD

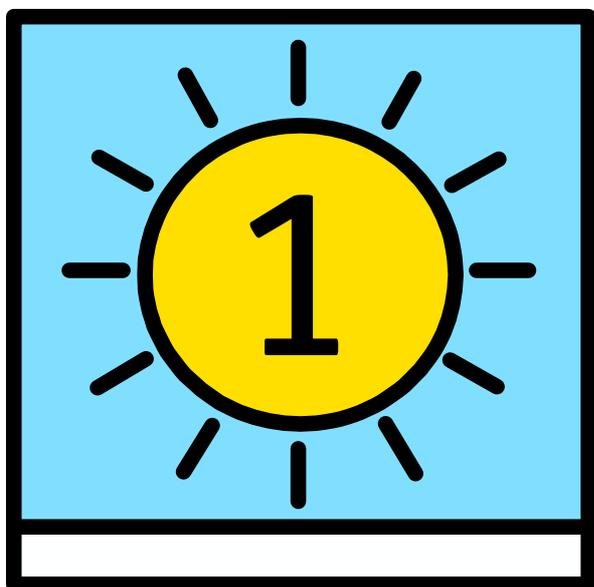
[www.childrenschoicetherapy.co.uk](http://www.childrenschoicetherapy.co.uk)

[childrenschoicedept@hotmail.com](mailto:childrenschoicedept@hotmail.com)

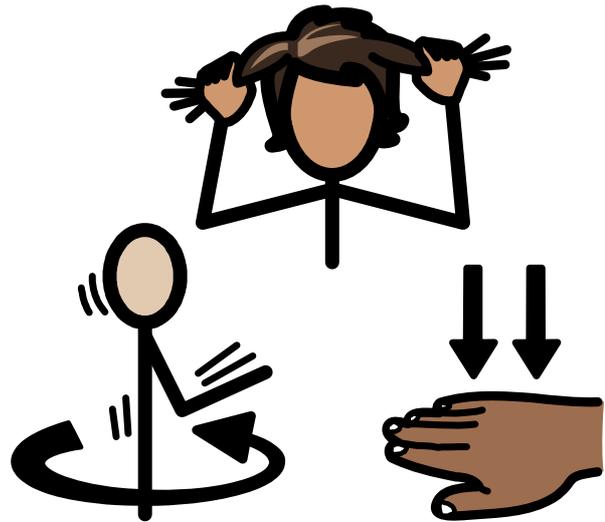
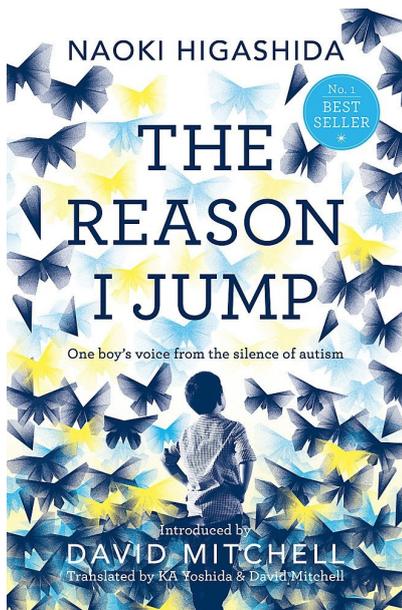


*'For any parent receiving an autism diagnosis for their child, remember your child is the same child who walked in that room prior to the diagnosis. This diagnosis will not change that, this will enable them to get the support they need to thrive!'*

*'You know your child best, trust your instincts & reach out to those who "get it"'*



*'Take a deep breath! Don't think too far ahead, just take one day at a time. Find your tribe, go to support meetings and workshops on how to best support your child (and you!).'*



*'Firstly, read the book called 'The reason I Jump.' It's a wonderful insight to the mind of a non speaking child and helps explain why many children do certain things.*

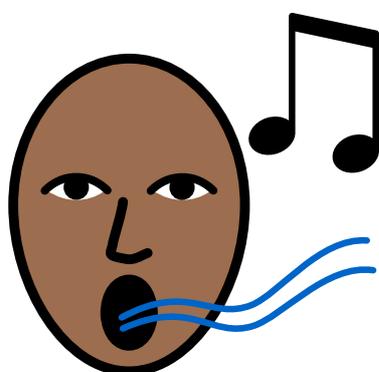
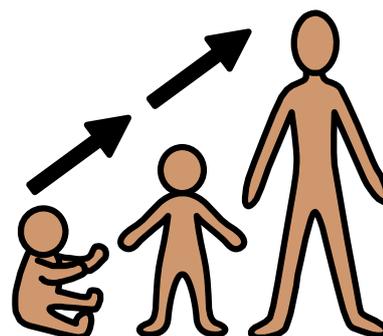
*Secondly seek advice and information from the actually autistic community, read their books, watch their documentaries (The Chris Packham one on BBC is wonderful). Do not relay on just professionals to tell you what to expect from your child being autistic. Only someone who is autistic can do that.*

*Find a community of other parents who are going through something similar, it can be lonely, you may lose friends and be given poor advice but it's really important that the autistic community is listened to. After all , your child is (and always has been) part of that community.'*

*'I'd advise anyone on the journey to not be scared. Trust your instincts. If not listened to at first then persevere. Build a case, gather your own evidence, even if school are not on the same page as you. We're the parents and we know our child!*



*'Find people who understand what you're going through it REALLY does help!'*



*'I've got more from music than words with my son so sing sing sing! It can be hard to communicate with your child especially when they don't want to, but as they grow your relationship grows and you find you become more in tune with each other and a lot of the issues you had calm down or go completely.'*

*'Sunshine Support are AMAZING. They have really good online webinars but some face to face stuff too if you can get there in Derby. Some of the staff are autistic and also have autistic children which makes a difference because they actually get it!'*

# EHCP help & advice

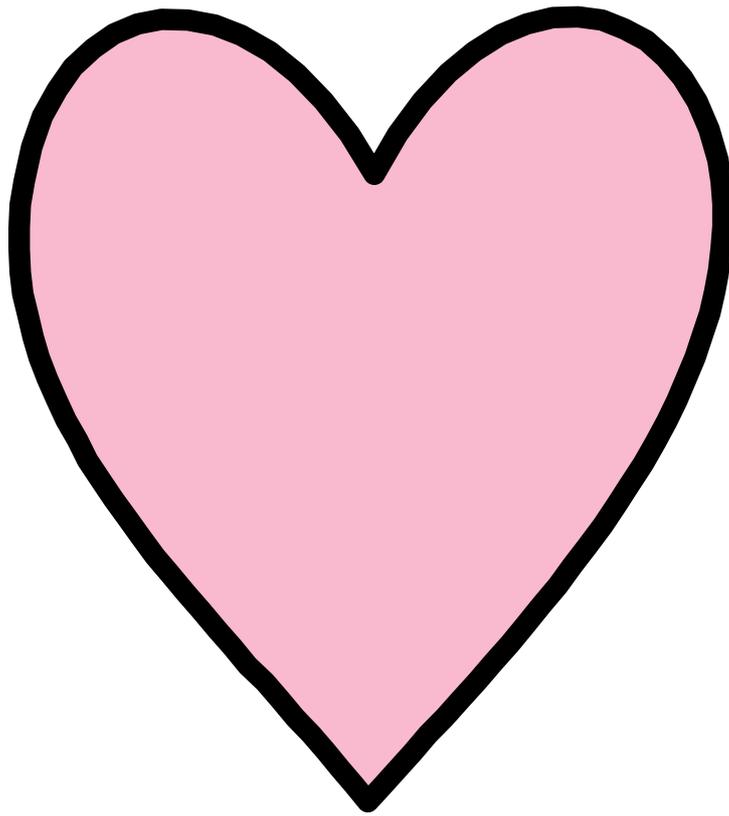
- FREE ADVICE CALL
- EHC NEEDS ASSESSMENT REQUESTS
- DRAFT REVIEW & ADVICE
- APPEAL & COMPLAINT LODGING SERVICE
- TRIBUNAL PREPARATION
- ACCESSIBLE ONLINE TRAINING
- SOCIAL EVENTS



**SUNSHINE SUPPORT**

Award-winning SEND Consultants and Advocates

REQUEST A FREE CALL: [sunshine-support.org](http://sunshine-support.org)



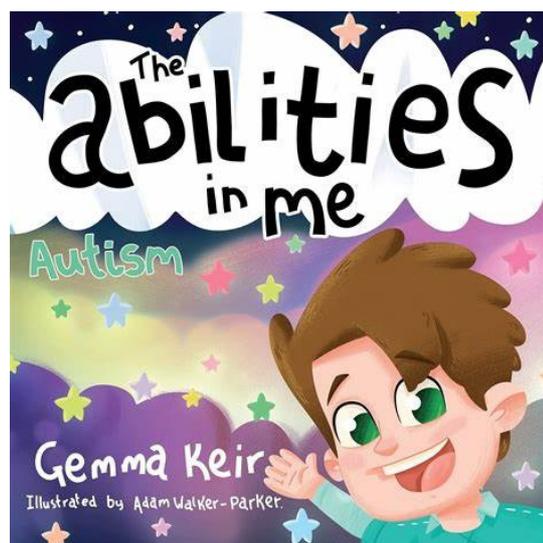
*'My advice would be, don't Google **anything**. The Internet is full of scaremongering and clinical information. It can be scary and makes you feel like your life will be sad and full of worry.*

*Speak to other SEN parents, find Instagram accounts, find carer support groups. Ready, Steady Communicate who uses Widgit symbols (same as school) helped us.*

*Your best advisors, and sometimes your new best friends, will be people with lived experiences. It's not the horrible life you have been told!*

*There will be extra challenges and things that you didn't think about when you thought of being a parent... but there will be amazing moments and you will love your child more than you could have imagined'*

*'The Abilities in Me Books.  
There is an autism one but lots  
of others too.'*

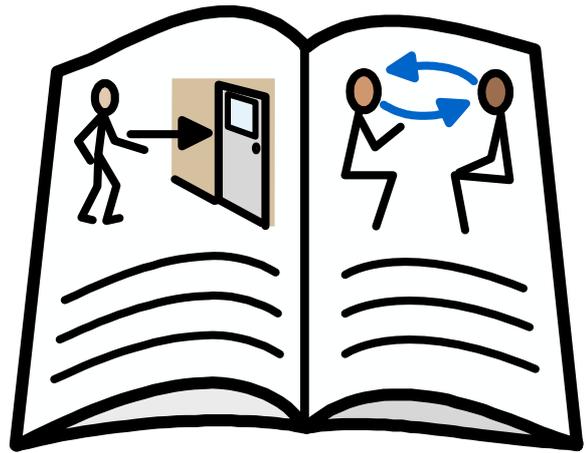


**National  
Autistic  
Society**

*'I found this link at the National Autistic Society useful around what words to use when talking about autism and autistic people. It describes what you should and should not say when talking about things to do with autism.'*

**[https://www.autism.org.uk/what-we-do/  
help-and-support/how-to-talk-about-autism](https://www.autism.org.uk/what-we-do/help-and-support/how-to-talk-about-autism)**

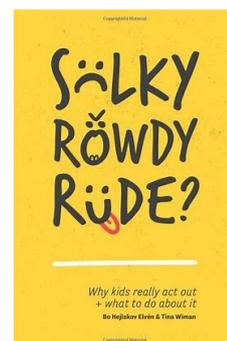
*'Deep breath, with no previous experience of the word autism then a diagnosis can sound scary. Arm yourself with knowledge....Please do not think teachers, support staff or even Drs will understand autism, you will have to be the biggest advocate your child has. Social stories really helped us and now I make my own.'*



*'You live with autism long before you are given the diagnosis. You know more about your child than any diagnosis can ever give you. Have strength in your knowledge and yourself. A diagnosis is not the end, it's just part of the journey!'*

Bo Hejlskov Elven

(Sulky, Rowdy, Rude book).



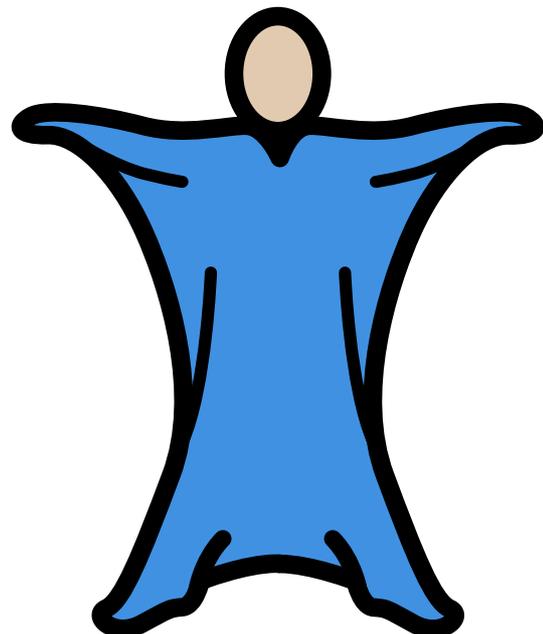


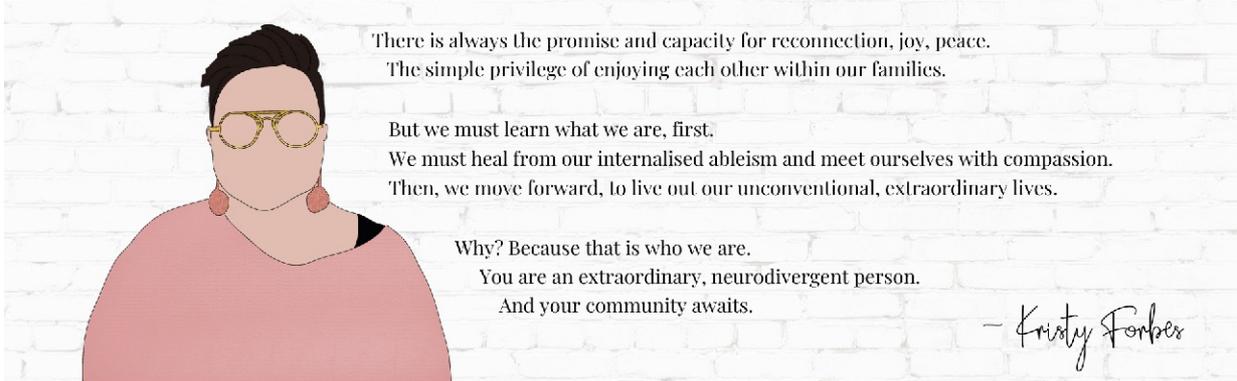
# Autism Education Trust

*'The Autism Education Trust (AET) have a progression framework that is more specific to autistic children. I think they do training too.'*

[www.autismeducationtrust.org.uk](http://www.autismeducationtrust.org.uk)

*'Get to know your child's sensory needs. It is not just about the usual 5 senses remember proprioceptive, vestibular and interoception. Your child might be over or under sensitive and knowing how to help them will change everything for them and you.'*





*'Excellent accounts that I follow and would recommend are*

- *Aaron Yorke, Accepting Behaviour*
- *Kristy Forbes - Autism & ND Support*
- *Dr Naomi Fisher*
- *Missing The Mark - blog and 1:1 consults for families*

*I'd be lost without all of these people. Most on that list are actually autistic.*

*I do also like Ross Greene.'*



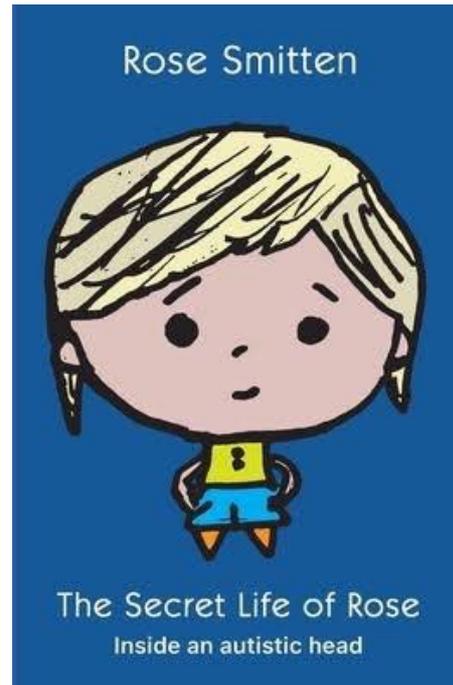
[www.kristyforbes.com.au](http://www.kristyforbes.com.au)



[www.missingthemark.blog](http://www.missingthemark.blog)

'Sooo many recommendations so here are a few.

- Libby Hill, *Small Talk*.
- *Talking SENSE! (EHCPs and SEND help)*
- Jodie Smitten
- Summer Farrelly (autistic young person on FB) .'



Jodie Smitten

BSc Hons Psy. PGCert, MA Autism, MBPsS

[www.jodiesmitten.co.uk](http://www.jodiesmitten.co.uk)

## We do...

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- Advocacy & support at meetings
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# SPECTRUM

**THE AWARD-WINNING AUTISM  
FRIENDLY FESTIVAL 16<sup>th</sup> SEPT 2023**

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**All tickets £15.00 each  
Under 3's FREE / 10am – 4pm  
[www.spectrumautismfestival.co.uk](http://www.spectrumautismfestival.co.uk)**



Spectrum Autism Friendly Festivals CIC Company Number 12337347

*'We go to Spectrum Festival in Derbyshire. It feels like a safe place because everyone there understands and my little boy can just be himself. Lots of happy stims.'*