

# DOS and DON'TS



Childhood from the autistic perspective  
✧ and how we can do it better ✧

## Testimonials

*"There's much to learn from it"*

*A great guide. It's quick and easy-to-use, and it touches your heart. At first it seems specifically addressed to parenting children with autism but it should be read by ALL parents to solve common problems we face with children nowadays. Patience and communication seem to be the keywords! There's much to learn from it.*

**Patty Liberti**

Teacher for children with special education needs and learning disabilities,  
& parent

*"Extremely approachable"*

*As a young person who has grown up facing the challenges of a world that does not understand ASD, 'Dos and Don'ts' is a welcome manual of advice. Very readable and comprehensive, this book would be an excellent starting point for families learning to support autistic children. I sincerely hope that parents who are struggling to understand their autistic children will educate themselves through books like this, and avoid causing unintentional trauma and stress to their children.*

*Filled with innumerable hints and funny cartoons, 'Dos and Don'ts' is extremely approachable, and would be an effective and practical guide for any family adjusting to an ASD diagnosis.*

**Felicity\***

17 years old, ASD, Australia

*"Yay, fantastic!"*

*Initial thoughts are 'Yay, fantastic'... what a super job you have done in creating such a positive, helpful, and useful book! I can see and feel all through how this is underpinned by wanting things to feel easier for people who would be assessed/ diagnosed on the autistic spectrum. It is also great to see that you have included the section on Trauma, as this is the area of my expertise (working on the neurological connections between body/brain/feelings/thoughts/emotions/connection with people, animals, and nature/physical play and movements).*

**Tamzin Baxter**

Project Worker (Trauma Recovery)  
Early Years Lead Practitioner (also practising in Family Therapy)

### *"I recognised loads of situations"*

*This is a brilliant wee book. I wish I had this advice when my family were growing up!*

*I absolutely love the illustrations and I recognised loads of situations that we as a family experienced. My children are now all young adults (my youngest was diagnosed with ASD at 13). Even if you think your child could be 'on the spectrum' use these tips to provide more structure and support in day-to-day life (easier said than done!). I think this could be a great little bible of how to promote a positive family life. Katy clearly has great insight and above all I like the emphasis on maintaining low stress and minimising the impact of over stimulation. Children with Asperger's pick up very easily on stress from adults. It can become a downward spiral if there is not the right intervention.*

*It is very practical good advice that reflects the realities of living with autism in families. I think the part on trauma and school refusing is very important to recognise in teenagers. I like the promotion of a very useful 'trauma' check list that every educational psychologist should read.*

*I would definitely recommend this to parents, teachers and any professionals working with families affected by Autism.*

**Jane Catlin**  
Parent, Scotland

### *"Rigorously researched"*

*This book is much needed. It's quick and light, but rigorously researched and full of pointers to further key educational and developmental research.*

**MJ Kinnear**  
Teacher & researcher, UK

### *"This guide will help parents"*

*I liked all of the do and don't tips (I especially like #5 on the top-tips don't list!) I think this guide will help parents be Sweet Peas towards their autistic children.*

**CockneyRebel\***  
Bank Worker, UK  
Diagnosed with Asperger's

*"For parents ready to receive it, one key tip or strategy could change their kids' lives"*

*I have autistic traits, and I'm also blind. There were definitely situations in Katy's book that I recognized from my childhood.*

*I believe that the viewpoints you've shared are very useful. To clarify, their usefulness comes from considering the child's perspective in the moment... adults can get really focused on coping with their own everyday parental joys and challenges, as well as their worries for their children in the long term. Maybe sometimes, they might forget the in-the-moment understanding of their children's experiences that Katy's book brings.*

*For parents ready to receive it, one key tip or strategy could change their kids' lives.*

**Data4B\***  
Writer, USA

*"Relevant and applicable"*

*Although this book aims to provide advice for those looking after an autistic child specifically, it can in fact can be relevant and applicable to anybody. As a teacher, I was able to take almost every piece of advice and apply it to all of my interactions with younger children (of which there are many in my life!), but also, on occasion, to interaction with people of all ages.*

*I think it is easy to forget that small activities and attitudes like these combine to make a very large impact on the development of a child. The book acknowledges that what is often seen as 'not a big deal' really does have strong and lasting effects on children.*

**Eve Francis**  
Primary School Teacher

*"Affirmations"*

*Warm fuzzy feeling inside – a lot of affirmations of what I thought, but I was looking outwards rather than inwards towards acceptance. Brilliant way of presenting this, Katy. I'd also like to say well done and thanks to you and your family, for pushing yourselves to do this for others when you didn't have to.*

**Omar Saleh**  
High school teacher & parent

Then come the questions -



# Author's note

This book started its life as a list of personal reminders jotted down in my notebook. I wrote it as two lists. What clearly worked, and what clearly *didn't* work when looking after an autistic child.

The two headings were written emphatically at the top of each page, in thick black pen. 'Do' and 'Don't'. I believe I can be rather obsessive about making detailed observations and taking notes.

I then consulted my list frequently when going about my daily life as a parent, 'Oh, now what did I write about what to do in *this* scenario?' Very often, the pause I took for consulting my notes meant a calmer resolution to the situation. And that was even before I knew what my notes said.

The information I gathered for my list was based primarily on my everyday experience, as a parent and as a human. But this hands-on experience was accompanied by an enormous amount of research and reading. While my children slept at night, I delved into heaps of books, articles and scientific papers, discovering myriad online resources too.

I interspersed my reading with chatting with and interviewing dozens of autistic adults and teenagers. These saintly people patiently answered questions about their lives and feelings now, what they remembered about their childhood (the positives and the negatives), and how they believe they'd been affected later on in life by their childhood experiences.

It then struck me, when seeing how misunderstood so many autistic people felt (and had felt in their childhood), and again when I sought guidance from experts about parenting autistic children, how little material there was on parenting *from the autistic perspective*.

To my mind, and being on the autistic spectrum myself, this seemed quite an oversight! With the help of an encouraging friend, I decided the information I had collated might be useful for others too – well, it was certainly worth a try. And so this book was born.

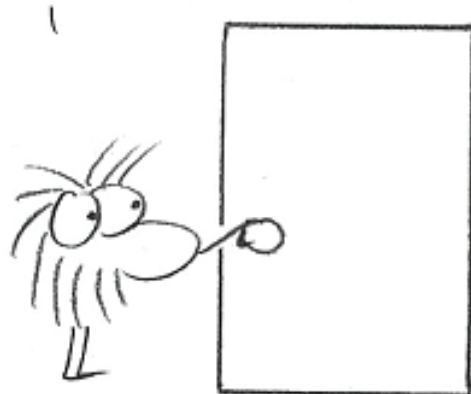
# And introducing ...

Fuzzy, our hero, without whom it would all be...  
well, just a bunch of words!



Matt Friedman, the illustrator, is also the author of the book *Dude, I'm an Aspie! – Thoughts and Illustrations on Living with Asperger's Syndrome*, and the website and blog [www.dudeimanaspie.com](http://www.dudeimanaspie.com)

What's outside my  
door today, d'you think?





*Many different ways of being autistic.* There can sometimes be major medical problems and physical disabilities associated with autism. The scope of this book and my own expertise could not hope to cover all of those.

Therefore, while aspects such as medication, meltdowns and school refusal are looked at in this book, some of the more extreme challenges may not be covered within these pages.

If you are struggling with any of those, and feeling overwhelmed by the practical problems involved in day-to-day life, besides seeking help from family and friends and any local support groups (e.g. parents' groups), you can also seek assistance from the welfare and health systems of wherever you live, if you have not already done so.

# Contents

Introduction	7
1. At home	9
2. Out and about	25
3. Friendship	37
4. Communication	47
5. School and learning	57
6. Food	67
7. Health and hygiene	73
8. Physical contact and emotions	81
9. Bedtime and sleep	95
10. Pregnancy and birth	99
11. Your own self care	105
12. Other top tips	107
A note on trauma	113
A bit of recognition!	117
Reading list	121

IT  
FITS!!



# Introduction

*Learn to listen to your heart and your instincts...*

*There are a lot of distractions, but those will lead you true!*

The aim of this book is to show a path towards recognising and trusting your innate instincts and knowledge as a parent. This path will lead to more joy and harmony, and a loving, strong bond with your child which will make many wonderful things possible.

Within these pages many practical tips are listed. Using these nuggets, children, and especially neurodivergent ones, can be helped and supported through childhood to become the most fulfilled and happiest version of themselves.

You may watch your child's anxiety levels fall. Their sense of self-determination, wellbeing, strength and confidence gradually increase. And as they head for adulthood they'll be feeling safer and more comfortable in themselves, having learned to trust the world more.

A lot of the ideas are relevant for all ages, but overall it is most relevant for younger children (from babyhood to about 10 years old).

The tips are not meant to be followed in a strict or systematic way. You need have no feelings of inadequacy and guilt if you don't manage to change or to do things 'right'. They are rather suggestions about things that might help, and intended for you to experiment with in whatever 'mix and match' best works for you.

It's as important to be forgiving and kind towards yourself as to those around you. If you feel at times that you're not coping and are not doing such a great job, these feelings are only too natural. All parents get them. Yours is arguably both the hardest and the most important job in the world.

We all need help, support and understanding from others. People are not designed to be parents in isolation. It's tough when it's expected of us, and even tougher when we are (as so often happens) individually found at fault when we 'fail'. Thankfully, we still have a strong instinct to reach out to others, in person and through books.

Freshly ground  
autism, sir?

Just a  
dash,  
thanks.



# Chapter 1

## At home

*Home is where the heart is.*

Home, for a child, is a place for feeling safe and nurtured among those who know you best. Spending quality time at home is important for all children, but becomes even more so for autistic children. They need plenty of time and peace to chill out, to indulge in any special interests, and to recharge their batteries. This is essential, as autistic people of all ages need to spend a lot of time in situations where they *do not feel anxious*.

### Do...

1. Spend plenty of quiet contemplative time; quiet time for your child to work on their own projects, time in nature away from shops, noise, traffic and artificial stimuli.
2. Spend time with animals. If your life allows for its continued care, consider adopting a dog or cat, or even just a hamster or guinea pig. A larger pet can however also be good for sleeping with at night, to offer company and reassurance.
3. Let your child wear clothes they find comfortable, and if they have sensory problems, you can order seamless socks online and cut out labels from clothes. It can feel like real torture for an autistic child to wear uncomfortable clothes.
4. Respect preferences expressed by your child where you can, even if they don't make any



sense to you (e.g. not getting head wet under the shower – why not wash in the bathtub instead? Or refusing to wear jeans, or the expensive shoes you bought – why not stick with jogging trousers and sneakers?).

**5.** Nurture your child's interests – perhaps building, science, music, art, or looking after animals and plants. If your child has a special interest, see what you can do to help locate resources and mentors for them.

**6.** Provide lots of sensory play for young children using sand, water, earth, playdough or clay, materials and fabrics, art supplies (e.g. large rolls of paper and large bottles of washable paint).

**7.** Provide lots of creative, sensory, hands-on experience in everyday living. Even very small children can help with baking, cooking and gardening (don't be too fussy about the results!)

**8.** Ask your children for help and collaboration with household tasks, and accept all forthcoming help cheerfully.

**9.** Go easy on suggestions and corrections when you're child's 'helping out'. Leaving the room to go do something else is quite a good strategy, if I feel myself getting tense... and if you're anything like me you can also apply it when your partner changes the baby or loads the dishwasher.

**10.** At breakfast each morning (or in another appropriate moment and setting, depending on your family's habits), try to dedicate a few moments to looking together at the overall plans for the day. Making a pictorial calendar with/for your child can also be a huge help here.



*Playdough.* For small children, making playdough can be a lot of fun. You use white flour, salt, water, and food colourings (Tip: add the colours to the water in a glass, it works best and it looks lovely). Besides being a great way to learn about mixing colours, the dough feels and smells nice, and it's often played with for hours afterwards (then store it in a bag in the fridge).

*Choose your battles.* Consider your priorities, and decide which specific areas you really need to be firm in. This will leave you to be flexible on other areas that you find less important. If you're firm on everything, you'll only end up totally exhausted, plus having your children live in dread of the sound of your voice.

My personal area of greatest firmness is kindness and consideration towards others. This includes helping out those in need and trying to make amends if someone's hurt (or at least always making sure to check if they're okay).

I'm not strict on things like neatness or table manners (except if we're at a wedding or in a nice restaurant, or at someone's house for whom that's important), or about using swearwords, making annoying noises, or playing messy games – though sometimes I ask the kids to take those last two outside.

*Obsessive interests?* If your child's special interest looks like it's literally becoming an obsession, to the exclusion of other important things in life, I'd recommend starting with concentrating on ways (many of which are described in this book) you can work on **reducing anxiety levels**.

You may find that if you succeed in doing that, your child's level of engagement in their special interest will naturally decline to a manageable level.

Having said that, if their special interest has any detrimental effects on themselves or others, you'll need to apply some redirection. For more help on this, Tony Attwood is very informative and helpful on the topic, dedicating a whole chapter to it in his *Complete Guide to Asperger's*.



*Special interests for soothing.* Observing this link between a child's anxiety levels and how much time they want to spend on their special interest, it's useful to understand how the special interest can at times serve this other important purpose besides just plain enjoyment (which it however also clearly provides). It can maintain emotional equilibrium in stressful times.

Here is an example: my son used to use his strong interest in cars to help him to diffuse his stress after challenging social situations. We would go outside and walk around the car park. He would compare all the car models and their maximum speeds until he felt relaxed again. It became clear to me how important an intense involvement in one's special interest can be for wellbeing and equilibrium during certain phases in life. Truth be told, I have a strong tendency towards having what some might well call 'obsessive' interests myself.

**11.** Try to give a few minutes' warning before going out, or anything else that will require changing activity.

**12.** Help your child when they ask you to, wherever possible, even if you don't understand why, or you do not think what they are asking for help with is important. If you do this by default, you will find that when you ask for help in return, they will usually comply quite willingly.

*Household chores.* I don't find it strictly necessary to assign specific chores to people (though at times it makes sense), because of the importance of *flexibility*.

Recognising when other people need help and what with, and having the momentum to give that help spontaneously, seems an essential part of being a happy and active member of the family, and of the wider community too.

No need to apply any rewards or punishments for chores, beyond the logical things like 'When we've cleaned up, we can go out!' or 'Just as soon as you guys have laid the table, we can eat'.

*Help me out here!* I try really hard to make sure everyone helps out in the house, mostly because I'm darned if I'm doing it all by myself! Also my mother pointed out that I wouldn't be doing my kids much good (in particular my daughter, perhaps) by modelling how to be an exhausted drudge.

Whenever I'm getting stressed because of being overloaded with too many tasks at once, instead of flapping about getting more and more overheated, I say 'Right, everyone. This is what needs doing'. We then sit ourselves briefly down at the kitchen table and write out a list of tasks.

The kids are now so used to this that they spontaneously come out with 'I'll lay out breakfast!', 'I'll feed the animals!', or whatever.

**13.** Allow stimming (hand flapping, making noises, rocking, and other repetitive actions). Do not try to impede it, or in fact criticise it at all. It's essential for self-regulation. It will also provide useful clues for you about your child's state of mind, allowing you to act accordingly.

*Self-stimulation.* A friend pointed out that a problem with being allowed to stim unimpeded is that there is often some social stigma and judgement attached.

Good point – perhaps one can try to avoid situations/places where people are unfriendly and intolerant (even when things are explained to them), and certainly to make sure your child is not going to be at the mercy of those people.

Thankfully, understanding about autism is growing, and with it tolerance. This is thanks to parents and autistic people speaking out to raise awareness and bring about change, and to initiatives like Sesame Street and *Our Amazing Children*.



*On 'Reinforcements'* – Threatening punishment or offering rewards for things can be problematic. You may have already found these more coercive techniques to be less than ideal. They often turn out to be ineffectual in the long term as they don't cultivate self-motivation.

Personally, I have found they are not very effective in the short term either as (with autistic kids in particular) they often don't seem to produce quite the intended results!



### ***Screen time – the bane of the modern parent!***

What are the effects of screen time on your child? Here are some:

#### **Positives:**

- ✦ Offers some downtime to an exhausted parent.
- ✦ Can be a lot of fun and educational.
- ✦ For older children it can be great for having a social life and friends online.
- ✦ Provides an opportunity to become really good at something and, through that, gain valuable self-confidence.

#### **Negatives:**

- ✦ Takes time away from other pursuits.
- ✦ By overstimulating, can heighten anxiety, jumpiness and nervousness (and reduce length of time to meltdown).
- ✦ Exacerbates, and can even cause, problems with attention span.
- ✦ Over time, can result in low self-esteem and depression.
- ✦ Can give rise to a huge and terrible boredom whenever the child is doing anything besides being on the screen. That's because it's one of the few things kids can legitimately do that are known and proven to be *highly addictive*.

**14.** Keep artificial lights not-too-bright (using dimmer switches or low-output bulbs). Avoid using fluorescent light bulbs.

**15.** Avoid too much **screen time** by applying rules and providing attractive alternatives.

*Providing alternatives to screens.* This doesn't mean, 'Hey, why not read this nice book instead of playing your video game?' (Even I can see the pitfall in that).

But you can take the lead on fun outdoors activities, games, reading and audiobooks, outings and so on. And arrange regular holidays or at least weekends away with no electronic devices or screens. There may be outcry at first but people will soon get used to the idea.

On journeys, audiobooks and music are great as you can look out of the window and daydream (daydreaming is a really undervalued skill in our culture).

*Having Rules.* Here are some suggestions. Prepare to be firm!

- ✦ No screens in the car (audiobooks or music only).
- ✦ TV only in the evening, and even then a) not right before bed and b) only films, series, or documentaries (not flicking about watching short videos and adverts on TikTok or YouTube). Making this a family activity is ideal, but perhaps not always possible.
- ✦ Video-gaming (yes, finally we got here!) – now my kids are a bit older they have from 5pm till dinnertime every weekday evening. That's it. It's been hard but I'm a very determined person. I hold the codes to all the devices. Now, it is rather like the sun rising or setting (that's just 'the way it is').

*On boredom.* If your child often complains about being bored, look at their screen time. Also, look at how much influence they have over important decisions affecting their own life.

The article *Boredom* by Perri Klass, Harvard Medicine journal (<https://hms.harvard.edu/magazine/adventure-issue/boredom>) gives some interesting insights.

HAVING SAID ALL THIS: Parents are often (usually?) stressed, tired and overloaded. The use of an electronic device often provides an urgently needed few minutes of peace, or else makes things possible that otherwise were not. (I used to allow my son to game on his Ipad while I cut his hair. It was the only way I ever discovered that he would let me do it while he sat still, with an itchy neck, for ten whole minutes.)

Your sanity is of vital importance. So if what I'm suggesting here (reducing and even going without screens in certain situations) feels tough, please go easy on yourself.

**16.** Show curious and impartial interest, if your children do spend time online, in what they spend the time doing. *'Hey, so in this 'Minecraft', are you really mining for something?'* etc. If they're anything like my kids they'll really enjoy enlightening you. This paves the way for them being happy to tell you, both now and later, quite a lot about their 'inner world'.

**17.** Read books and comics together, and download your child's favourite audiobooks (for car journeys, etc.). The best way to get your kid to be a reader is by never forcing it on them (not allowing screens is usually enough), having lots of books around, and reading a lot yourself. But reading is not for everyone! Don't force yourself. It's way more important to be enjoying life.

**18.** Say how you feel (keeping it brief and relevant to the situation), even if you're cross or tired. This will make it much easier for your child to understand why and how you are acting. They can then make observations and allowances for it. However,

*Fiction and non-fiction.* This is great for both independent research and for developing a powerful imagination. Stories and novels (and fictional films, dramas and series) also stimulate and develop our empathy, as we live our way through the story from someone else's point of view.

*Less stuff!* Consider decluttering, maybe enlisting some outside help if possible. Having a lot of things gives you even more to worry about. You could also arrange toy-swaps with friends, especially for more bulky items. Kids are usually more excited about seeing fresh toys or ones they haven't seen for a while.

make sure you say it in a way which simply states facts and does not put *any* blame or responsibility on anyone.

**19.** Try to be as minimalist as you can, within reason. Autistic people, more than most, need things to be orderly and tidy (even though that is a burden for their parents to bear!)

**20.** Ask friends and relations to please *not* give a lot of toys and gifts to your children. Especially not large ones (certainly not without consulting you first).

**21.** Try to approach exasperating situations with patience and humour. A bit of laughter makes everything, however hard, more palatable.

**22.** Provide access to musical instruments, and play favourite music at home and on journeys.



**23.** Dance together (and/or with other members of your family), to your favourite music. It's so much fun!

**24.** If plans change, explain what's happening. Even when very little, your child needs to know what's going on. Being consulted and informed gives them the feeling of control over their lives and leads to proactiveness and flexibility.

**25.** Spend time in companionable silence, either working together on a project or just alongside each other, each busy with their own work. I love working in this peaceful way with other people (pruning trees or picking fruit, painting model figures, cutting out cookies, shelling peas, building brick models and finding pieces, etc. – the list is endless).

**26.** Play family parlour games like charades, consequences, acting games or guessing games.

**27.** Live in the moment, take plenty of time to enjoy life. Take things slowly, *enjoy!*



## Don't...

- 1.** Don't give love and approval only on a conditional basis.
- 2.** Don't criticise, or put down. There are other ways to effectively demonstrate preferred ways of behaving. Usually the best way is by modelling, though the occasional well-timed and sensitive suggestion can also be useful.

*When you're tempted to criticise...* Ask yourself searchingly if what you are asking for is really desirable or necessary (or reasonable). Is it helping towards the longer-term well-being of your family and child?

Anything with motivations such as social embarrassment, other people's expectations, or conformism for its own sake, examine carefully whether it is really necessary to change behaviours.

A general rule can be to ask yourself 'is it harming anyone?' If the answer is 'no', reconsider making it an issue.

3. Try not to expose your child to bright lights and loud noises. They might find them quite distressing.
4. Don't have too many toys, in particular bright, loud plastic ones. Better to have a few good quality toys so you and your child can keep them in good order.
5. Don't expose your child to disturbing films, images, or stories about people (in particular animals and children) being severely hurt or badly treated. Your sensitive child will do better without receiving too much information about anything cruel or unusual (especially visually), regardless of your ideas about the importance of staying informed about current affairs, or seeing the latest films in order to be up-to-date with peers.
6. Don't feel you have to keep routines inflexibly. Getting used to different places, people and things, while keeping a stable base of loving relationships, can mean your child doesn't get too fixated on sameness. Sometimes there are unavoidable changes in life. Long term it's better to have inner stability and not be relying too much on external things which might get lost or broken, or on restricting and sometimes burdensome routines.
7. Try not to live in a general state of unresolved conflict within your household (if this is humanly possible!) You are likely to find that an autistic child will be acting as an amplifier. This will not alleviate your pain and stress, to put it mildly.

*Being brutal vs being honest.* Honesty and openness about natural phenomena such as death and reproduction (in the right moments) are, however, essential.

If for example a beloved animal dies, I believe it is far better for your child to be brought gently to understand this, and even be involved in a burial (for example), rather than to have the pet disappear and then only vague or inaccurate explanations be given.



**8.** Don't give too many options, too frequently. Your child may be saying 'no' to things by default, even if they might want them. You may be asking them to make too many decisions per day about things they don't care much about. You know your child, you know what's likely to be their feeling on many occasions (whether they like/want things or not). Follow your instinct. You'll get quickly corrected when you guessed a preference wrong, and you'll know for the next time.

**9.** Don't overdo it on the 'health and safety' front. If given a chance to try (preferably without a grown-up hanging over them anxiously guiding them through every step), most kids are perfectly capable of many feats that they are now usually prevented from doing (e.g. using a knife, lighting a fire etc.).

When allowed a good level of autonomy, children become agile with their bodies and hands, inventive and resourceful, and well aware of what they can do (and of their limitations). In the long run this is how your child will become not only manually skilled, but also become good at evaluating risks and making decisions.

*Often our routines make us feel safe and secure,* so it's important, when making any changes, to be careful and respectful of your child's feelings. The idea is to gently move toward an equilibrium, where the child doesn't get too stressed but the needs and preferences of other family members (not least yourself!) get respected too.

So if making changes will result in any distress, introduce them at first gradually, step by step, and focusing very much on the palatable and positive until your child gets used to idea of being okay with change, even on a small scale at first.



*Overall harmony.* If you aren't happy, or aren't living in relative balance, fairness and honesty with yourself and other family members, it might be time to start considering carefully what can be done about it.

*No such thing as Utopia.* I'm not saying there should be no arguments in the house. Living without any conflict would not only be impossible, but (I think) undesirable too.

Having a disagreement. Getting upset or just showing and/or saying that you feel hurt. Then, through flexible two-way (or more, if other people are involved) communication, getting around to understanding each other's point of view. This whole process allows for figuring out solutions that work to an acceptable degree for everyone. It's great modelling for healthy conflict management and settling disputes constructively.

**10.** Try not to be dramatic when giving health warnings (e.g. describing in detail to your child the terrible things that could happen if you don't wash your hands after touching the cat, or if you were silly enough to drink the paint). Your child might be very impressionable and prone to developing real phobias about things, which can be incredibly hard to eradicate.

**11.** Don't say 'no' as a default. Make 'yes' the default, unless there are good reasons why not. Explain what those good reasons are, when you do need to say 'no'.

**12.** Don't take it too seriously when people (especially when they are not family or close friends) say you are overprotective of your child. *You* are the expert here.

**13.** Don't expect your children to notice if you need help in the house, or respond to your hints (or complaints) about it.

**14.** Don't use emotional blackmail. (Guilty, guilty! I have to consciously work very hard on myself not to do this.) This

*Physical safety over emotional safety.* In our culture, we generally emphasise our concern for the *physical* safety of our children, while having rather a tendency to disregard their *emotional* safety.

This may have more to do with how we deal legally with liability (i.e. how others can be held liable if things go wrong), than true levels of danger and risk, and the possible damage to the individual, that are attached to various things/activities.

It's relatively easy to make the link and hold third parties to account when a child is physically hurt. But if the child is psychologically suffering because of factors in their environment or experiences, it's much more complex, harder to track, and of course nearly impossible to gather empirical evidence on it.

includes heavy sighs (for the benefit of those around you), and rolling your eyes, and reproachful looks at things like the dirty pots that someone else should have washed up. Instead, speak up! Some mild cursing and humour will work better than passive aggression and resentful self-sacrifice.

**15.** Don't take away treasured objects, or get rid of any possessions (including clothes, however worn-out!) without asking first. It makes the world unpredictable and unsafe. It's also not very respectful – imagine what you'd say if one of your family members did the same to you.

*Asking for the help you need.* It's better to make requests openly and directly. Be specific, direct and neutral. Reminders might be necessary, but again neutrally – avoid starting to plead or criticise at this point.

Neutral one-words are good e.g. 'Shoes' or 'Table' (pointing).

You can also give choices, e.g. 'We need to feed the animals and lay the table. I don't mind, what's your preference?' You can be flexible on timing if the job permits.

*Wi-fi available only at certain times.* If you like this idea, at home you can attach your modem to a timer (maybe under a table in a dark corner). That way it isn't you having to be directly responsible for it.

**16.** Don't say 'don't' (yes, I know! Blush!) Try clearly stated rules (which apply to everyone), e.g. 'Shoes off at the door', or 'WiFi is switched off at so-and-so time'. And give information in a firm manner e.g. 'that tea is scalding hot', or 'this is a very steep slope'.

*Why shouldn't I say 'don't'?* A rather unexpected side-effect of saying 'don't', is that children literally hear the expectation in what you say (i.e. you're asking them *not* to do it, but your expectation is that they probably *will*). So you say, 'Don't touch the oven' and they promptly do so.



Free!  
Free!



# Chapter 2

## Out and about

### *Head for the hills!*

Being out and about can be fun, stimulating, and a great learning experience too. Finding that life can be wonderful, while a little unpredictable, is a key lesson for any child – especially those with high sensitivity levels who are prone to anxiety. Having said that, there are challenges to it, as most parents know only too well. If you manage to find a good balance, this will have the double effect of increasing your child's trust in the universe *and* developing their resilience in the face of challenges.

### Do...

1. Go slowly, living in the moment as much as possible.
2. Make sure there is access to somewhere quiet and calming, on demand (if you are in a city, you can find calm and quiet in public gardens, libraries, museums or art galleries).
3. Spend time in outdoor noncompetitive, non-structured activities e.g. biking, swimming, climbing, ice-skating, sledging, walking, horse-riding, fishing, boating, and camping together with friends or family.
4. Regularly arrange to see friends and relatives – giving priority to those you and your family find kind and non-stressful.
5. Find play parks with lots of space and few people (or go at times when they're quiet). Swings, see-saws, roundabouts,

*Swings and roundabouts.* There are some types of movement that seem to be particularly good. Trampolining, swinging, and other activities that involve jumping or spinning around can give great enjoyment and satisfaction.

*Getting away.* We prefer woods and lakes to Disneyland (it's also cheaper), but you can focus on your own family's preferences, so wherever you all feel relaxed and happy. Avoid being in a hurry or being goal-oriented. Take time to observe your surroundings and be together, bring along your child's book and your own, and maybe a pack of cards and some binoculars.

climbing frames, slides and trampolines are great fun, and exercise too.

**6.** Travel. Consider camping or renting a cabin in places you love. Even just for a few days it can be a refreshing change.

**7.** Whenever possible, give a good few minutes' warning before changing setting e.g. leaving the house, leaving a playground, the beach etc. Make sure you get an answer confirming they got the message – if they're concentrating on something else they may not have heard a word you said!

**8.** Aim to arrive early to appointments. Leaving much more time means you'll be less stressed when setting out, and the journey will be pleasanter (and possibly less dangerous) than otherwise.

**9.** Avoid places where overstimulation is likely. For example, shopping malls, supermarkets, and any other crowded, noisy places with artificial lights and little natural green or sky. Try to go shopping and out for other activities at times when few people are around, even if that means changing your routines. Be relaxed, take time, involve your child (they could find items on the list, push the trolley, choose the fruit, etc.).



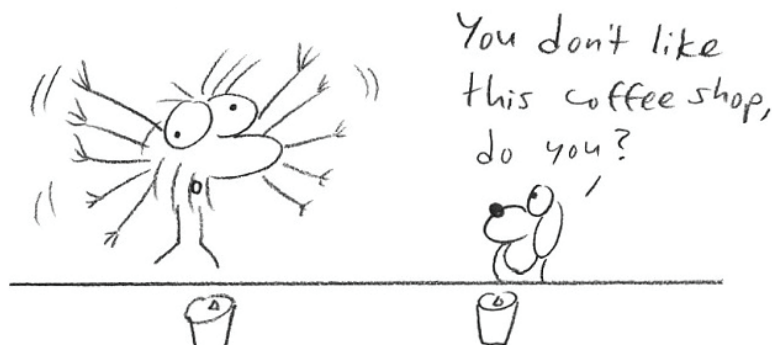
**10.** Avoid running errands with your child when you are tired and stressed yourself, or in a rush. This kind of situation could easily end in meltdown.

**11.** Avoid being in a hurry. Allow lots of time, wherever you go, for meandering and exploring.

**12.** Try to not have too many time-constrained appointments. I think one a day is generally quite enough, and at least a couple of days a week it's pleasant to have none at all.

**13.** Learn to recognise the signs of over-stimulation. Distress signals (though you know your own child best) could be anything from high pitched noises to repetitive movements or tics). Change environment as quickly and calmly as possible.

**14.** Avoid eating in crowded or noisy restaurants or cafes, or formal ones where you have to 'behave'. Maybe bring a picnic instead, so you can eat somewhere quieter and more private.





***Emotional and mental preparation.***

Children don't need anywhere near so much warning about *positive* activities that they don't find scary in any way. While, for those they may find difficult, they may need days of repeated reminders and emotional preparation.



**15.** Avoid running errands with your child when you are tired and stressed yourself, or in a rush. This kind of situation could easily end in meltdown.

**16.** Avoid being in a hurry. Allow lots of time, wherever you go, for meandering and exploring.

**17.** Bring your book or a magazine on outings, or go with a good friend, so you can sit down and enjoy the minutes you get while your children explore and play wherever they wish to (provided it's not the lion's pen at the zoo). Stop in places with space to play, preferably in nature with no structured activities. Bring a flask of coffee or tea along for the grown ups.

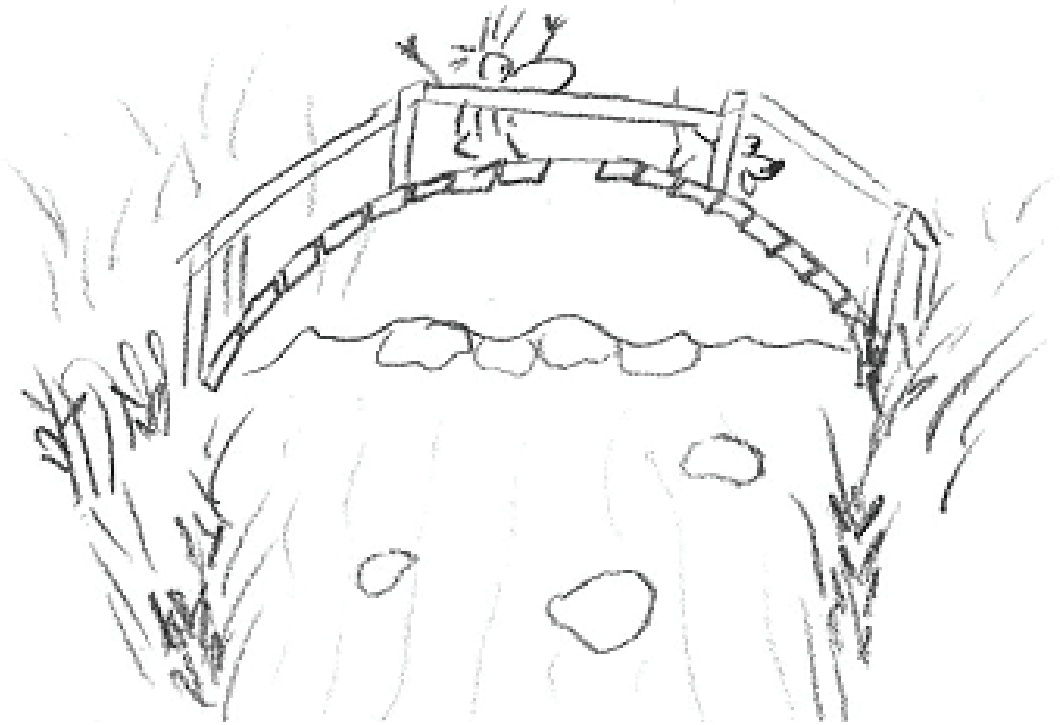
**18.** If your toddler hates being belted in, try to find strategies that make it easier for them. With high chairs and prams/strollers it's usually possible to find ways around having to firmly strap your child in. But if you're having trouble with the car seat, try giving your child as much autonomy as you can, as early as possible. The more they feel in control (climbing in, clipping themselves in), the happier they will be with the whole idea.

**19.** You can also try to make the whole 'going in the car' thing a positive experience. I used to pack little picnic boxes for my kids, to eat in the car once we were on the way. It was an effort, but they loved it.

**20.** Let your kid daydream in the car. Wherever possible, have music or audiobooks on in preference to giving your kids electronic devices.

**21.** Change scene. When everyone's irritable, or not really enjoying life, see if you can just get out of the house! Go somewhere nice, take a picnic or grab something along the way.

**22.** Make spontaneous decisions together about doing fun things. Hey, why don't we go to the beach, or lake? Yes, even with no towels or swimming things (if you happen to already be out)!



# Don't...

1. Don't be *too* well-prepared. Try not to panic if you've forgotten things; rather try to cheerfully make do with what you have. A parent who always carries everything one could possibly need makes for children who get fixed to the notion that you must have those things in order to be okay, and that it's a crisis if you don't.
2. Don't make your child do activities against their will. As far as possible, let them back out of things even if they 'promised' they'd do something or previously expressed a wish to. They may have not properly understood or known what it entailed. Contrary to much popular belief, real self-discipline and perseverance come from inside a person, not from someone else imposing it.

## *Hey, how about we... ?*

Making-do not only means a lot less unpacking for you later, but it teaches an important lesson. Enjoying life, taking risks, being spontaneous... it's all part of living life to the full. This is a controlled way of showing your child that everything will be fine – even without being properly prepared or having the right gear!

But take care to keep these suggestions strictly optional. Your kid needs to know they were involved in the decision-making process. If their answer is negative, no problem. Leave it for another time. No need to act disappointed (You could even say, 'Actually, that's a good idea, let's go home and chill-out on the couch instead.')

Putting pressure on your child at this point would defeat the purpose. It would make them even less disposed to like any ideas you suggest in future.

Instead, make the next thing you spontaneously suggest *even more enticing* (something you know they really love!). Choose a moment when everyone's feeling quite perky.

### *What about unavoidable social obligations?*

Sometimes there will be family activities or outings which you are pretty sure will be fine for your child, and where others would miss out by not going. You can then make decisions on their behalf – if you are fairly sure it won't majorly upset them.

But don't bank on their participation. Have some comics, a colouring book, or a talking book, or a model or puzzle to do. If a child is not feeling sociable, they can then sit in a quiet place working on an individual project.

Explain to any adults who aren't naturally understanding about a child's need for a bit of solitude and quiet time. I believe it's a societal bias we need to address – an intolerance for introversion.

3. Don't warn your child often to 'be careful' as it can have a paralysing effect. They'll become fearful of some unspecified danger, and helpless in the face of that. Instead, give specific warnings only when necessary. Try to frame them as calm observations e.g. 'This is a very busy road'.
4. Don't become a slave to carrying around ridiculously large and cumbersome objects, or to unrealistic and onerous routines that make your life a misery.

*Making changes?* You'll need to be gentle and patient with your child, and have an awareness about the reasons behind their attachment to a particular routine or thing.

A brutal 'no' will generally *not* be the best way to achieve your aim of liberation. Your relationship and their equilibrium are at stake – both of which are very important things!

A better method is to take small, experimental steps towards liberation by offering alternatives, small compromises or alterations. Take gradual steps towards making your life a little easier. Lorna Wing gives very good advice on ways to do this in her book *The Autistic Spectrum*.



*How'm I supposed to be cheerful and spontaneous on top of everything else?*

If your life is stressful, hurried, and full of multitasking (as so many, many parents' lives are) it may seem like pie-in-the-sky to be relaxed or cheerfully make do. If someone told me I should relax in times when I've been stressed or overloaded, I'd first be furious, and probably (if they insisted) start weeping!

There are times when tight control is all we have left, and if we lose it we're acutely aware everything will go wrong very quickly. Please go easy on yourself and recognise yourself for what you are (with or without the occasional panic attack) – a superhero!

If things feel impossible it is ALWAYS down to the situation you are in. It's not you. Never say, 'I can't do it.' Say, 'It can't be done.'

**5.** Don't regularly give in to sudden emotional outbursts about wanting stuff (anything from ice creams or sweets, buying your child their one-hundredth Lego model, or having other members of the family cater to random whims that unreasonably limit their own lives).

*Requests for things.* As a rule, if kids can relatively calmly explain why they need/want something, or even if they just say seriously, 'This is very important to me', within reason I would recommend doing everything you can to help them out.

I'm thinking of families I know where you don't see the children having 'temper tantrums' very often. I'm observing people who habitually spend time with their children, who listen with a high level of attention and respect to one other. And who have enough 'down time' available in their lives to be able to do that.



### *Meltdown!*

It's obvious that right now your kid is feeling totally overwhelmed and downright awful. Figuring out the reasons for it and the patterns behind it is really important, as often there are ways to avoid it happening. Here are some possibilities for why they might feel that way:

If the meltdown happened **more-or-less spontaneously** (apparently out of nowhere):

- ✦ They may be suffering from sensory overload.
- ✦ They could be tired, hungry or feeling too hot or cold.
- ✦ Perhaps they reacted to a trigger which brought up some painful memory or past experience (a sort of 'flashback'). Think of 'classical conditioning' where we unconsciously link things with not-usually-connected things. If you suspect the presence of such a trigger, take notes on the situation. You may start seeing patterns.

If the meltdown happened **as a result of someone requiring or requesting something from them, or vetoing something**:

- ✦ Maybe they are just overwhelmed (see above).
- ✦ Maybe they *often* feel little or no control over what's happening – both from moment to moment and in their lives overall.
- ✦ Maybe they *often* feel not listened to or not taken seriously.
- ✦ Perhaps they *often* feel they're put into situations they can't cope with or where they feel powerless or defenseless.

If a request for something is accompanied by a sudden outburst of strong emotion I think you can be reasonably certain that it's not so much about the professed *thing* they want, as about the emotions and triggers it—or the situation—evokes.

6. Don't automatically give sweets and treats to a child who's having/just had a meltdown, or give them your smartphone, or put them straight in front of the TV.
7. Don't, however tempting, wipe it from your memory once it's over. Take notes on the situation and have a think about it and how to mitigate these scenarios in the future.
8. And finally, don't forget that episodes like this leave bruises on both you and your child. Usually just emotional bruises, but I know some parents need a good supply of arnica in the cupboard (yes, for themselves!). So, allow for some healing time and pleasant activities once everyone is calmer.

*Anaesthetising emotional pain.* When you hand a crying child a lollipop or an Ipad, you're basically giving them an introductory course on emotional numbing. My sister gently pointed this out to me when, in front of her, I gave my boy chocolate straightaway when he bumped his knee.

Distracted from both the pain and the real reasons behind it, we quickly learn to self-soothe. We use food, drink, media or retail (or any of the myriad other things available in our culture for this purpose).

We've learnt to cope by anaesthetising ourselves, and have become world experts at ignoring, denying and running away from any painful feelings about things.

The downside is, of course, that longer-term solutions such as change or healing, cannot take place. Ach, let's just say it's not a great solution in the long run!



*What to do in an 'unreasonable demand' situation?*

- ✦ First, make it clear that you're not going to buy the Lego, or fly to Mars (or whatever it is), briefly giving the reason why not. Make it clear this is not up for argument right now. You could mention you're happy to discuss it later, in a different and less stressful situation.
- ✦ If they get upset at this, stay calm, sit with them or near them, having a cuddle if that's accepted.
- ✦ Ignore any unhelpful looks or comments from random people.
- ✦ When possible, check if your child is hungry, thirsty, too cold, too hot, or just very tired.
- ✦ After a minute or so, start pointing out passing things they might be interested in. If this is met unreceptively, stop. Just stay close by giving off relaxed and loving body-language as much as you can (And if anyone says to you parenting is easy, you have my permission to thump them...)

**Other suggestions.** You could try telling a story, or (if you're in the car) unobtrusively putting on their favourite song or talking book.

If your kid is extremely angry with you (and you're the only grown-up present), maybe their teddy bear could try telling a neutral story, or chatting to them – it's a well-kept secret, the usefulness of ventriloquy in parenting. And sometimes, giving your child what they wanted 'in fantasy' can work. 'Gosh, I wish we could fly to... not just Mars, but ALL the planets!'

If your interventions (trying to be friendly, or talk) are just annoying your child even more, stay quiet, stay close, be unobtrusive.

Fall into a meditative space, if at all possible. Try to imagine and visualise a specific time when things were loving and harmonious with your child. And remember this child in front of you is the same one – just they're a little upset right now!



*Mending the relationship and feeling listened to and safe.* In a meltdown moment, your time and/or patience will be exhausted and your energy maxed out.

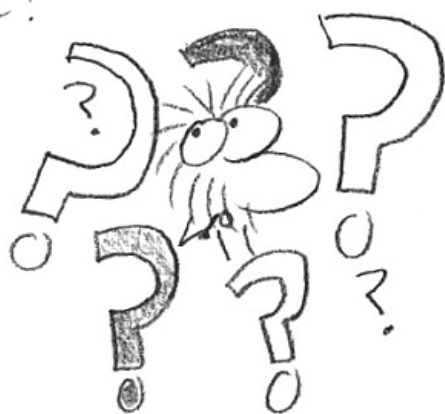
It's essential therefore – before it all disappears into the mists of the past – to dedicate a good amount of time in the near future to doing something enjoyable and relaxing together.

If it seems appropriate, you can also talk together about any ways in which anxiety and stress levels might be reduced overall. I like the Adele Faber and Elaine Mazlish method of brainstorming with your children (see reading list for more information). Here, you write down all suggestions from both parties, no matter how wild, and then look through them together. I have done this quite a number of times with my kids, for various reasons.

In all of this, the message you're giving to your child is yes, you love them. Yes, you care, and take them seriously, enough to dedicate real time and thought to them. In fact, in other circumstances you will carefully listen and consider, if they show you over time how much they really want or need something.

But no, you can't and won't race about catering to frantic demands for random things that are highly impractical and inconvenient at that particular moment.

Then come the questions -  
am I answering right, wrong,  
incomplete? Nobody knows  
but me!





Company.



A crowd.



Crowd-ed.



Get  
me out  
of here!

# Chapter 3

## Friendship

*Loyalty, honesty.*

When we think of friendships among children, we may imagine groups of same-aged children hanging out in play parks or in the school yard. With your autistic child this is unlikely to be the scenario. And, as much as our cultural bias may tell us otherwise, this is actually not a bad thing.

You can instead work to your child's strengths. Autistic people can be truly loving, loyal and empathetic friends. They tend to prefer one-on-one interaction, and their closest friends won't necessarily be of the same age, gender, or social sphere as them – in fact, in many cases they don't even have to be human!

## Do...

- 1.** Nurture one or two beneficial friendships. You can tell which those are by how your child acts during and after an encounter with someone. Are they looking relaxed, happy? Do they seem to feel good about themselves?
- 2.** Bear in mind a lot of autistic children prefer older people to kids their age, and friendships don't have to remain in any specific age group. Close friends can also be family members.
- 3.** Spend time with people who love your child and see their good qualities. In particular, seek out people who see them as an interesting and special person, and who feel some connection

with them, maybe due to similar interests. At a later age, consider mentoring as an option, perhaps by an adult on the autistic spectrum, who might know how to recognise and bring out your child's strengths.

4. Follow your child's lead on who they wish to be friends with, observing who they really connect with and who they have a positive relationship with.
5. Avoid competitive situations, or situations where anyone is compared unfavourably with anyone else.
6. Avoid situations where your child feels any pressure to conform or pretend in order to be accepted by others.
7. Introduce new social situations and challenges in steps you think your child can probably deal with.
8. Observe closely what constellations of people your child seems to like best. When they feel confident within a small circle of good, loyal friends (they may at first prefer to see one friend at a time), they are much more likely to eventually be able to interact happily and confidently in more diverse group situations.
9. Make sure you socialise in situations you can both get out of easily, without any hassle or comments. Observe closely what happens and you can adapt your strategy accordingly.
10. Follow your child's lead about how much socialising they can manage, using their feeling as an overall guide. This way they have the chance to grow stronger and more resilient in the long run. Having faith and relaxing – that's the challenge (for the parent)!

*'Too sensitive'*. Is it a good thing for a sensitive child to be regularly exposed, against their wishes, to stressful competitive or hostile social situations from which they have no means of escape?

Often in our well-meaning attempts to 'toughen up' our shy, sensitive children, frustratingly they seem to get even more anxious, fearful, and negative.



**11.** Be aware your child will need to get proper periods of downtime from socialising with other kids. Use these as times you can hang out quietly together. Make it clear that not only do you not mind, you really enjoy it and see it as a chance to get closer.

**12.** When your younger children meet new kids, observe how things are going. If anyone is in difficulties, you can intervene with some optional, non-competitive activities or games, or by reading a story, and/or also just spend a little time yourself playing or chatting (gently and unobtrusively) with any child who feels hurt, frustrated or left out.

**13.** See if your child would enjoy any special interest clubs (if available in your area) on topics they're keen on. In particular, they might like groups or clubs where people work alongside

*Directing the dynamics during play.* I think of this as a bit like moving stones to get a stream going in the desired direction. Soon (when the kids know each other and have settled into a natural positive dynamic) you will need to do very little, and eventually nothing at all.

Children who find social situations daunting often find it easier at first to relate to others when there is some structure offered.

*The risk of overwhelming a 'best buddy'.* In school situations, obsessive clinging to one friend as a point of reference is common in autistic children (and in fact in any child who is feeling insecure or unsafe in the situation). If you consider how overwhelmed and insecure your child might be feeling, and their propensity for one-on-one interacting, you can start to see why.

Nurturing an additional friendship can therefore be helpful, as it is better not to have all your eggs in one basket! However, it's important to only do this in a natural, no-pressure way, or you risk making your child feel more insecure.

You could help nurture additional friendships informally e.g. by creating opportunities during the holidays to get to know another schoolfellow who they like, or spending time with the child of close family friends, or a cousin, even if of a different age.

one another rather than in teams or groups. Just bear in mind that unless it's a really small and/or gentle group they may find the social element stressful and prefer to follow up their special interests alone or with a like-minded mentor.

**14.** Arrive early at parties. This allows time to become familiar with the environment, and means not being faced with an overwhelming crowd on arrival.

**15.** Help your child to find quiet space and time alone quiet space and time alone or just with a carer or friend, during parties or gatherings. Later they will know how to do this on their own.

**16.** Explain certain traits to others e.g. that if they have to say your child's name ten times to get their attention, it's nothing personal. Or that it's necessary for your child to drape themselves around you and stay there, when they begin to feel socially overwhelmed. Or that being touched and physically manipulated without their consent is not something they are likely to respond well to.



17. If it feels right, you can help your child in making sense of interactions with others. You can, in a neutral tone, tell them how people are likely to feel or respond when you say or do certain things. Autistic people are generally fond of logic, so studying outcomes ('if I do this, he/she does that') can be interesting – but *only if* done without any pressure, judgement or expectation.

It's important to pre-empt any problems with *physical contact* by speaking beforehand to doctors, teachers, (especially those teaching subjects like sports, dance or gymnastics) and other parents.

These days there is a lot more understanding around autism. People will be generally quite understanding about your child's ambivalence around being handled or touched, or being in very close proximity to others.



*Unusual social skills.* If your child's attempts at social interaction are unusual, be accepting of them and encourage others to do the same. This will help your child to become more confident in making further attempts. When people are given the chance to understand, they may be more tolerant. They have the chance to then like and accept your child for who they are.

I come in  
peace!

|



Yeah yeah yeah,  
C'mon, "ET,"  
let's get some  
lunch.



**18.** Do your best to model enjoyment of life and loving relationships. Take time, be kind, be contented, be loving, as much as you can be. If your life does not seem to permit these things, consider any ways you may be able to change things for the better, if it is within your power to do so! Though please don't feel guilty about things you cannot change. I know there is not always the freedom to make lifestyle changes.

*Bad behaviour?* It seems to me that autistic children, when they 'melt down', are often responding to either truly nerve-racking situations (where we are all busy hiding our emotions or reactions about it), or else other other people's hidden manipulations or competitiveness.

Like litmus paper showing up acid or alkaline, their outward behaviour can be showing up either peace and kindness, or stress and incongruence in their surrounding environment.

**19.** Make it clear that it's fine to change your mind, and model this by, when you do it yourself, giving a proper explanation (and an apology if appropriate) to those who may be affected by your change of heart. This is an essential skill, and will result in an adult who is strong and true, but also flexible about listening to others' points of view, and responsive to changing circumstances.

**20.** Keep in mind that any difficult or antisocial behaviour is extremely likely to be an immediate response to stress.

**21.** Have some strategies up your sleeve for dealing with situations of conflict with other children. The following points deal with some of those strategies.

**22.** State to the children firmly what things are for e.g. 'Sand is not for throwing, it's for playing with.' You can also give relevant information e.g. 'When it's thrown around it can go in people's eyes'. These things can be said loudly and firmly: you want to see

*Rowdy play.* At any point when something looks painful or even just very unequal (e.g. more children jumping on just one child, or a bigger child wrestling a much smaller one to the ground), even if they are all laughing, I step in and say 'WAIT A SECOND! David (example name), are you enjoying this game?'

If the answer from the crushed or chased child is 'No' (even a shake of the head), I say firmly and loudly, 'Games are only fun when EVERYONE enjoys it. If there is any person not enjoying it, it's NOT A FUN GAME anymore'.

If the child states positively that yes it *is* fun (this can just as easily happen), and confirms they are in fact enjoying the game, then I let them continue.

Sometimes however, before letting them go on playing (especially if the game involves people saying, 'Stop, stop, no, NO!' between shrieks of laughter), I get them to agree on a word for when someone *really* means 'stop!' When that word is said, the other players know they're serious, and it must instantly be respected.

whatever's going on stop immediately. You could then state a rule in a firm tone e.g. 'No throwing stuff in the sandpit!'

**23.** Keep a very careful eye on any roughhousing. Be poised to intervene, and do so as soon as you are in doubt. You can do this by stating the rules firmly e.g. 'No hitting'. If physical intervention is necessary, keep it peacable, neutral, and as gentle as possible. I have found myself literally standing between children who are trying to hit or kick one another, at which point it can get a bit silly, especially if I was baking and have really sticky hands.

*Hurtful play.* When children begin to go wild and hurt one another, they are stressed or overstimulated.

A child who is angry or otherwise apparently behaving unreasonably is, in my experience, feeling either overwhelmed or hurt by the others and/or by the situation.

Considering this, some redirecting is in order. You could initiate an alternative collaborative activity – e.g. 'Ooh, I know, we could dig a moat together and then fill it from the watering can. We could even make some paper boats to float on it!'

If at any point, despite your interventions, a child has clearly just Had Enough, ask them to come in (or aside) with you. They could have a story read to them if they want it, or be offered a drink or snack. You could suggest a quiet game or activity together – or else they could help you in what you're doing.

If the other child/children then seem keen on joining in (as they all too often do), make it clear by your demeanor you don't believe anyone's to blame for mishaps or upsets. But still, keep a very careful eye on how everyone's treating each other. The children need to feel you'll keep them safe (yes, even from each other!)

When children are older they'll know how to seek some quiet time and space by themselves.

**24.** Outside moments of extremis, it's good to emphasise that we *never* use violence. Explain that if you're upset with someone it's much better to say what's up, if that seems at all possible. If you let someone know when they upset you, you've given them a chance to change and/or make amends. But if you find it's impossible to do that, or else you tried but the situation did not get any better, then (I tell the child), straightaway come and find me (or whichever other grown up is around).



## Don't...

- 1.** Don't compare your child, or anything about them, unfavourably to others.
- 2.** Don't extoll the virtues of being outgoing, sociable, outspoken, or anything that your child clearly is not.
- 3.** Don't put your child into obligatory social situations, and groups/crowds where there is no option for getting away.
- 4.** Don't place a lot of importance on being smiley and chatty in social situations. Some people are better at listening and appear more serious than others. You can make it clear to your child that it is perfectly acceptable to be an observer. Susan Cain's presentation *The Power of Introverts* (Ted Talks, [www.ted.com/talks](http://www.ted.com/talks)) gives a bit of perspective on this issue.
- 5.** Don't assume your child's best friends must be other children. Their friendships with adults can be just as, if not more, important.
- 6.** Don't tell a child off, or comment on their their behaviour or actions, in front of others. If you have to say something

specifically to them, in that moment, find a way to bring them unobtrusively to the side first.

7. Don't focus on enquiries into 'what happened?' when your children have been hurt or upset during play (among themselves or with their friends) and you didn't personally witness what the cause was. Instead give your attention to the injured party ('are you okay? Where does it hurt?'), offer some comfort to them and possibly suggest another fun activity (e.g. 'shall we get the paints out?' or 'let's bake some cookies!')

If the child you suspect may have caused the upset then perks up and says, 'Can I play too?', hold no grudges. Just say, 'Of course' with a warm smile, and then you can spend the next minutes directing their play together into something more positive, and making sure everyone is being respected and treated kindly.

*'It wasn't me!'* If you consistently focus on the injured party and how to make it better for them, *instead of* what exactly happened and who's responsible, you'll find the kids (provided that there are not other major negative factors playing in their lives) begin to a) resolve their conflicts constructively without even calling you, and b) when someone is hurt, respond automatically, 'Are you okay?' (instead of, 'It wasn't me!')

If any children are busy chorusing their excuses and insisting on their innocence when another child is upset or hurt, I say, "I'm only interested in knowing 'what happened' if someone got bitten by a snake – in which case I'd want to know what the snake looked like. Let's see – what can we do here that might actually help?"



8. Don't use your children to try to make yourself look good (with a modest smile which says 'look everyone what clever/helpful/ obedient/athletic/etc. children I have!') It will backfire on you. Trust me. I've tried it.

9. Try not to be too socially isolated. If your situation permits, it's good to sometimes, in as relaxed a way as possible, be around other people you like and trust. I know this can be tricky, and also how much effort it requires! Especially if your child is not the only one in the family who's on the autistic spectrum.





# Chapter 4

## Communication

*The exchange of thoughts, messages, or information, as by speech, signals, writing, or behaviour.*

### Do...

1. Let your child communicate within the family in their own way, even if that is non-verbally. You don't need to insist on the use of words if you in any case understand what they mean. Refusing to respond or reply when you understand your child can inflict unnecessary emotional trauma.
2. If you get an 'inappropriate' response from your child, ask yourself about the context and what you really meant, or how you felt when saying it.

*Self-confidence.* Your child is much more likely to learn how to effectively communicate with others if you give them secure foundations of self-confidence on which to build.

You may occasionally be able to help them communicate effectively by making mild and neutral suggestions (preferably when solicited) about how to be understood by others, and how words can be used—though never do this in social situations or indeed in front of other people, even family members. However, you may find any prompting to be unnecessary as they will learn through their own observations.



*For non-verbal children.* If your child is non-speaking but clearly desperate to communicate, look into using Facilitated Communication and/or AAC (Augmentative and Alternative Communication), which has changed the lives of many autistic people and their families. For more information, go to [www.aacandautism.com](http://www.aacandautism.com)

3. Try to be understanding about your child sometimes not paying attention, and about forgetfulness. It's not intentional! It may be annoying sometimes, but on the flipside you have a child who can *really* concentrate on things they're interested in.
4. Set realistic and reasonable boundaries and stick to them them as much as possible. This provides a reassuring structure.

*Inanimate friends.* Go ahead and give some of your child's teddies, dolls, puppets or toy animals characters and voices (pretend, initiated by you).

They can often be really useful in providing funny, unthreatening love, reassurance, friendship (e.g. in cases where a child has been traumatised by experiences with real people and needs to develop basic trust again).

They can also sometimes be a channel for your child to bring out and work through feelings of anger, frustration and hurt.

If your child becomes upset or angry when you do this, stop immediately. It's a very good indication they are quite angry with *you*. Anger always comes out of hurt. This is useful information, and it may be a good moment for some self-examination (which, as I know from my own experience this is both a painful and—unfortunately—often necessary activity!)

I'd suggest sewing labels onto any teddies or toy animals your child is particularly attached to, with your phone number and a 'please return me!' message. We learnt about this the hard way.

Autistic children are not usually good at *mixed messages*. They sense and respond much more to an atmosphere than to any words that are spoken or outward appearances. On the plus side, from what I've seen, they show an almost allergic reaction to manipulative or underhand practices.

Your autistic child generally won't parrot social niceties or go along with the charade. If they respond to you in a seemingly odd or irrelevant way, consider the possibility they may be responding to the other side of a mixed message, or an unintentional undercurrent of feelings from you or others present.

My own theory is that everyone is, to some extent or other, socially a little bit nervous (I believe that's why so much alcohol is consumed socially among many of us adults!). Autistic children can perhaps pick up on all of our nerves in these situations – and amplify that about a thousand times.

5. Have rules about important things. You can state those aloud in moments when it becomes necessary. This way you don't need to get personal. You can say, for example, 'Dinnertime is for sitting down. *Outside* is for running around.' You're allowed to sound a bit stressed (it's quite natural, after all!)
6. If your child has a tendency to be autocratic (to try and dictate to you and other family members what to do and how to do it, and not to seem very willing to try to see your/their side of it), be consistent about making sure you and others get listened

*Being flexible.* However if, for example, your child is melting down (if they are perhaps stressed or exhausted) you might need to provide a get-out clause. For example, 'Do you want to come sit with me on the sofa for a bit first?' or else 'Hey, if you really need to let off steam shall we ...?' (Blank is provided for whatever your preferred method is. Ours would be taking a break outside and throwing a ball for our dog).



*Avoiding character judgements.* Being firm must be accompanied by obvious unconditional love of the child themselves, and absolutely no blame or character judgements. Whether these are direct or indirect, they are extremely counter-productive.

Examples include 'You're selfish', 'You're clumsy', 'You have to learn to consider other people', 'Civilised people don't behave like that', 'Look what you've done.'

to and that your and their needs and wishes are respected too. This is essential, for everyone's wellbeing.

7. If there is resistance to seeing others' points of view, be firm but limit yourself to brief statements that say a) how you or someone else might feel in a given situation, and b) observations/information about the situation. E.g. 'When I'm criticised I feel deflated.', and e.g. 'It looks like your sister is trying to say something.'

*Out of control, yikes!* In the search for control, children are actually desperate for something else: SAFETY.

Quite contrary to how it appears on the surface, they need to see that it's okay to actually *relinquish* control, and that nothing bad will happen if they do. They will not be made to do things or put into situations they can't deal with.

It has to feel safe to really trust, in both other people and the universe. (Though I know, as things stand, that is a hard lesson for a parent to impart!)

*With great power comes great responsibility.* It is not just considerate for other members of the family, but for the child themselves to not let them rule the roost. It is really scary for very young people to be given the power to dictate things – unquestioned – to their family members, even if it *seems* to be what they want. Actually, power over your family also means responsibility for what happens to them, and that's far too large a burden for a child.

**8.** During hard times, when treating others badly becomes a regular occurrence (in my experience this happens when there is bullying going on – either at school or in other areas of your child's life you are not in control of), try calling a Family Meeting, in which you can take a collaborative look at what Rules there should be in your home.

**9.** If in conflict situations your child tends sometimes to see things as very black and white (and their own view as being the only correct one), try to be neutral but firm. The message you want to get across, loud and clear, is: 'Me and you are two different people; of *course* sometimes we are going to want different things, or see things differently'.

*Family Meeting; Family Rules.* In our case, we sat down together as a family and made a big and beautiful poster called 'Family Rules'. The children wrote out all the rules we agreed on, and we illustrated it together.

The main themes were 'No name-calling or verbal abuse' and 'No violence of any kind'. The children's final contribution at the time was 'Grown ups: No shouting'. Hmm.

We stuck it on the kitchen wall and, for a time, it was quite frequently referred to.



**10.** Make it clear just because you have different views doesn't mean anyone's to blame, and it certainly doesn't mean you stopped loving your child! You can add that of course you're not perfect, by any means, in fact sometimes you make a right pig's ear of things, but you're doing your best. Every one of us messes up sometimes, it's an unfortunate part of being human.

**11.** Keep the emphasis firmly on loving each other and each person doing their best. If you can manage to then jointly find compromises to your differences in beliefs or needs – now, there's an achievement!

**12.** Indulge in interesting conversations with your family members, e.g. at table or on walks. Make sure all contributions get listened to and considered.

**13.** Be aware that your autistic child might have difficulties with metaphors and figures of speech, and a tendency to take things literally. Explain any idioms.

**14.** Have some fun using some very silly humour illustrating things like metaphors and exaggeration – maybe saying totally

*Other people's perspectives.* Reading fictional books and stories and watching fictional dramas and series' can really help to mitigate black-and-white thinking. Since they were small, my kids would often ask me questions about the moral dilemmas and conflicts represented in the stories.

I would strongly recommend sticking to *good, real* dramas and fiction... and never stories produced on purpose to 'teach' children something, and even sometimes coming ready-packaged with questions that children are supposed to answer, about what *we* think they should have noticed or learnt about the story. (I'm afraid most autistic children can smell an agenda about a mile away!)

The child must be left free to make their own observations and build their own ideas. Answers to questions (their own, spontaneous ones) should be brief and to-the-point, unless more information is requested.

over-inflated things, or making very silly comparisons, so they can get the idea that this is not actually true but rather just really ridiculous and crazy things you say when you want to share a joke with people, or for super-special effect.

*'Let's build this bridge right up to the sky!'* (Then you can jump up and down trying to 'touch' the sky, unsuccessfully.)

*'That meeting made me feel like my head was being crushed by a heffalump.'*

*'Let's burn that bridge when we get to it!'* (That happens to be my own favourite mixed metaphor. I believe it took the children quite a number of years to understand a) why I said it, and b) why I would then fall about laughing, every time...)

## Don't...



- 1.** Don't enter into battle mode with your child, i.e. a situation where you range yourselves against one another. You're on the same side! If you feel this happening, look for help and advice. The books *How to Listen so Kids Will Talk, and Talk so Kids Will Listen* and *Siblings Without Rivalry*, I found very helpful in this (see Reading List).
- 2.** Don't always keep your phone on. Instead, give priority to being fully with your children, listening to them, talking and interacting together.
- 3.** Don't say, 'It's not that bad', or, 'But you have to see it from their point of view', if your child goes off on a rant about someone or something.



4. Don't force your child to say 'sorry'. The best way anyone can learn about really feeling sorry and being able to find ways of making amends to people, is by those around them modelling it.
5. Don't lie, or hide important information from your child (though of course you may have to tone things down sometimes if your child might be too hurt or disturbed by them). The child will sense untruths and be confused. If you feel you cannot answer or explain something, simply tell them so.
6. Don't swear at your animals (even if they pee on the carpet). Your child is likely to be a quick learner here, and might demonstrate their new skills in quite the wrong moments.
7. Don't assume that your child's acts and behaviour are done on purpose to annoy or manipulate you. Especially in very young children, and especially if they're having an expressive outburst

*'It's not that bad', 'You should look at it from their point of view'.*

Your message may sound really positive and moderate, but that's deceptive. Its actual effect is to be absolutely infuriating to the recipient (thereby making them look even worse), while allowing you to feel rather good about yourself (what a superior human being you are!).

It also expresses underlying disapproval at their outburst.

So the outcome is your child will quickly learn it's better not to share their feelings of disappointment with you, and they will retain their bitterness.

Try being understanding instead – after a few minutes the ranting might conceivably become milder, possibly followed by a pause, and then, 'Hmm, but I suppose from *their* point of view...'

of emotion, this is unlikely to be the case. Anyway, even if it were the case wouldn't we still need to ask ourselves why they feel the urge to do it?

8. Don't tell anecdotes about your child when they are present (yes, even stories which show them in a positive light!) without every time first obtaining their explicit and freely given consent.
9. Don't force or even encourage your child to make eye contact with people. There are good reasons why autistic people sometimes find this very difficult.

Laurence Heller and Aline LaPierre's book *Healing Developmental Trauma* is particularly useful on how to help and support anybody who has *difficulties with eye contact* (dedicating a whole section to it).

And in the meantime, your child might find that there are certain tricks help them deal with eye contact in social situations – for example, they could look at a person's hair, or eyebrows.

*Phone etiquette.* Try not to interrupt your children by pulling out your phone whenever it beeps (unless you are waiting to hear from a very sick relative).

You can enforce, and lead by example, a 'no phone at the table' rule when sitting together, whether at home or out.

At home your phone could be kept in a certain spot, to be occasionally looked at or answered – rather than in your pocket (or in your hand).







# Chapter 5

## Learning and School

### *Understanding and knowledge.*

A lot of our ideas about learning and teaching come into question when it comes to our neurodivergent children. When we do things by standard methods, much of the time learning just ain't happening, and anxiety levels are rocketing.

It's almost as though we're talking different languages. And, if we don't manage to learn theirs, our child may simply withdraw and give up. So how about changing tack? We could allow the child to take the lead, providing a different sort of space, where growthful things can happen.

### Do...

- 1.** When being asked questions, in particular repetitive ones, be patient. If your child asks the same question and seem fully satisfied with hearing the answer over and over, they may be checking in with their reality to feel secure. However, if they register frustration when you answer, you may well be talking at cross purposes.
- 2.** Audiobooks are a great resource for enticing children into the world of books and reading. When they become very into a book or a series of books, you can get those hard-copy books and put them on your shelf. Your child will very likely pull them out and peruse them, fascinated (especially if they contain illustrations).

*Talking at cross purposes.* An example of this is my son asking about the treatment of animals. He asks, 'WHY do they keep chickens in factories?'. I answer, 'So they can sell them in supermarkets.'

Two minutes later, 'Yes but WHY do they keep them in factories?' We could continue going round in circles like this for a long time, and I could get exasperated, or assume he's not very bright. Ah, or... am I *not* answering the question he is trying to ask me?

When I instead answer, 'It is awful, isn't it – but luckily more and more people realise this and try not to support it by not buying the meat', he seems satisfied and later says to me, 'Can we buy all the chicks from the factory, and set them free?'

3. Follow leads on your child's passions, build on their strengths, and assist them in finding places and people where they feel at home.
4. Avoid making your child do activities they don't like and aren't good at.
5. During conversation with your child, listen to their interests and opinions (even if they seem weird to you). Try responding in a curious, uncritical way, and make an effort to avoid bringing the topic around to what you think they should be interested in or learning about. You might find that you learn new and interesting things during these chats.

A didactic approach to parenting does not make for friendship and relaxation. In fact, it greatly inhibits your enjoyment of being together. Ironically, it also has the effect over time of diminishing your child's natural enthusiasm for learning.



*Character building.* I find questionable the much-applied idea that it is somehow character-building to be forced by others to do things you don't enjoy and aren't good at. I found Alfie Kohn's studies quite informative on this, confirming my instincts (see Reading List).

On the other hand, what is clearly shown to be character-building is to have the opportunity to find goals you really want to achieve, and then to see that the way to get there is though hard work and perseverance (even on parts that you may enjoy less than others).

This is something that a person can truly learn only through their own volition. It's worth noting that even very small children show an amazing talent for understanding and doing this, if they are given the chance to do so.

6. Drama/theatre games and activities may be enjoyed by some children. These pursuits can be useful for practising different roles, conversations and situations.
7. Make up stories and songs about things. This is actually a great way of imparting knowledge (e.g. about geography, history, politics, art etc.), as for some reason, where a textbook might make us fall asleep after a few minutes, an adventuresome narrative has the power to keep us gripped for ages – and even remember some of the details afterwards!
8. Follow your own interests, showing your child how much you enjoy them – that is, the process itself, not just attaining

*Living in the moment.* Give your child time and space to digest what's happening, to explore their surroundings, to follow up on interests as they feel the urge. In short, live in the moment and enjoy the process, look around you instead of keeping your eyes fixed on the distant horizon as you rush towards it. Horizons have an annoying habit of receding.



goals. If it's a competitive hobby, show that you love it in itself and not just for the sake of winning.

9. Do lots of scientific experiments (you can get many great books and look up online, safe experiments that you can do at home). This helps your child to put together ideas about how the world works, how it looks and feels, what it's made of etc.

## Don't...

1. Don't be goal oriented. Rushing from goal to goal is unlikely to be your child's learning style.

2. Don't insist on 'age appropriate' material for your child's learning. With an autistic child this is destined to go wrong. They might be amazing at something unusual, or that they're not meant to know for another ten years – and show zero interest or ability in something they 'should' have learnt years ago.

3. Don't indulge in constant correction. It's unnecessary and eats away at both self-esteem and joy of discovering about life.

4. Don't override your child's natural sense of what is right and wrong through correction, instruction and testing. Imagine a system that's in the process of developing and learning, and the controller continually applies 'override' when the system is still busy figuring things out for itself. How far is that system going to develop, and how independent is it going to become?



*Difficulties reading?* If your child has trouble learning to read, rather than putting pressure on them at a young age, try watching films, documentaries and series' always with the subtitles at the bottom. This way, they can learn 'by osmosis'.

*On testing children.* In his book *How Children Learn*, John Holt (who was a schoolteacher himself for many years, a nationwide consultant for American schools, and then went on to become a world-renowned author and expert on learning) describes this as, 'Sitting on a chair that's only just been glued, to see if it's stable'.

Quote: *'When we constantly ask children questions to find out whether they know something (or prove to ourselves that they don't), we almost always cut short the slow process by which, testing their hunches against experience, they turn them into secure knowledge.*

*Asking children questions about things they are only just beginning to learn is like sitting in a chair which has only just been glued. The structure collapses.'*

5. Don't support or agree with other adults (e.g. teachers or other parents) when they put down your child, or place blame or judgement on them. Especially never in front of your child.
6. Don't put pressure on your child to compete against others. Competition is likely to be damaging to extremely sensitive young individuals, whether they win or lose, as they both sense any hostility (even when it's carefully hidden) and are very sensitive to the pain of others.
7. Don't emphasise your expectations and air your anxieties about your child's achievements in their presence. Trust that things will happen in their own time, and limit yourself to

*Fostering love of learning and self-motivation in your child.*

Instead of pressure or expectations, you can provide a good learning environment. When they show interest in an activity, be encouraging and quietly supportive.

Encourage any contact with mentors, older children and other role models. Especially important and precious are relationships with adults and older children who clearly like and respect your child (and vice versa), and who really connect with them.

*On competitive activities for kids.* Even if your child is among those who outwardly love competing against others, observe how tense and vigilant, and at times obsessed, they become over it.

Consider carefully:

- a) Have they observed how important competing is in our culture (and how you can get acceptance and respect for it – something they may have been yearning for)?
- b) Does it look like it's doing them good, physiologically and emotionally?
- c) How close friends are they with the people they are competing with, and against?

If your child looks really relaxed and happy, and seems to be great, loyal buddies with their team-mates and competitors, then I would say whole-heartedly, 'Go for it!'

But if you feel ambiguous about this, maybe consider trying some other outlets that don't involve competing.

If possible, try exploring diverse non-competitive activities which use the gifts and skills your child has naturally. The aim is to ignite their enthusiasm, make them feel good about themselves, and gain self-respect leading to respect from adults and peers.

Note: I know how hard this is in real life. Most sports and activities are competitive by nature, and those which aren't are often made competitive, such as rock-climbing or swimming. My daughter told me how at school her class went out picking blackberries – and (she said, in amazement, having been homeschooled for a few years) this outing was presented by the teacher as a 'blackberry picking competition'.

helping them build up a good foundation of security and self-confidence.

**8.** Don't pressurise your child into taking a direction. Let them meander and explore. You can provide opportunities, and a constructive learning environment, but you'll have little hope of



*Home education or flexi-schooling.* If home education is legal in your country, consider whether it could work for you and your family.

Flexi-schooling (only going to school on a limited number of days in the week) is also an option in many countries, and is on the increase.

finding the specific thing/s your child will love and be good at if you don't let them take the lead on this.

**9.** Don't expose your child to cruelty or bullying. Follow your gut feeling on this one. There are many good indicators when your child is suffering from bullying when you aren't around to deal with it (e.g. at school or nursery).

**10.** Don't feel you have to make your child go to school if they are either refusing or really having trouble with it. Keep in mind that in a school environment an autistic child's anxiety can go through the roof. They may urgently need some down time.

## At school

Your child is likely to do better in a friendly neighbourhood-style school where the children already know one another and where there is an overall benign atmosphere. If the teacher/s emphasise the importance of being kind to one another, and tend to monitor this closely and be firm about it, then so much the better.

If this is not possible, then **having at least one close, trustworthy friend** becomes even more crucial to your child's happiness. If you



can find a way of being in contact with other parents of children in your child's class (ones your child likes), and socialising together in order to build their friendship, try to organise it. It could really be worth the investment.

If your child is already at the school, **is there a teacher/teachers with whom your child feels they really connect**, whom they trust, and who seems to appreciate your child's qualities? This could also make a world of difference to your child's school experience.

## Questions to ask

Here is a list of some of the questions you might find useful to ask about your child's school or potential school.

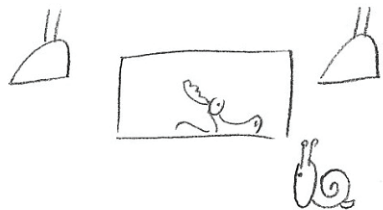
- 1.** Can children (even young ones), when they feel the need, go to a quiet private place – perhaps a common room or a 'reading corner' in the library, or, failing that, the nurse's room if there is a quiet calming corner or space there?
- 2.** Is it obligatory to go outside with the other children at playtime, or can individual children or even a pair of children stay in the classroom if they wish to do so?
- 3.** Are there special interest groups or clubs available, perhaps in the lunch break? If these clubs are small and of mixed ages they can be great for children who feel overwhelmed by large rowdy groups of same-age children. It's also a good opportunity for making friends.
- 4.** Is there an adult in the playground at all times (and if the school is larger, what is the ratio of adults to children in the playground)?
- 5.** Is break time 'stepped', i.e. to limit the number of children going out at one time?

*Supervision, intervention and activities during breaks.* Schools may even make a point of leaving the children to their own devices during break time, as—goes the reasoning—this is a good way for the children to develop autonomy and have some free unstructured time.

While I agree with this logic, I don't think it's a justification for not having sufficient adults monitoring and intervening on behalf of the vulnerable. There must be provision in place for children who lack friendship and protection.

I believe it's unwise to assume children who are used to a competitive style of education and upbringing are going to default toward being kind and inclusive toward one another, and tolerant of one another's differences, once left alone together. Actually there is, I believe, plenty of evidence to the contrary.

6. Do the adults present actively intervene and participate e.g. by initiating some non-compulsory structured activities in order to include children who may be feeling lost or left out? For this purpose the activities should be collaborative rather than competitive e.g. building a hide-out, circle gymnastics and dances (for younger kids), building a fort in the sandpit, making an obstacle course. Whatever the environment permits (I know some are really challenging; it's really not easy for teachers!)
7. Is there a mentoring system in place where older children are trained to help younger ones e.g. by befriending them, helping them find their way around, spending time with them in the playground (maybe playing ball, or whatever)?
8. Is there any greenery (grass and/or trees) in the playground?
9. Are there any school animals? Is gardening or caring for animals in the curriculum? I know this is a long shot, but it's worth asking!



- 10.** Can the sky and/or greenery (i.e. any natural light and scenery) be seen through the classroom windows (especially important if the children spend the whole day in the same classroom)?
- 11.** Is there a sandpit, climbing frame, roundabout, slide etc.?
- 12.** Are the teachers approachable, supportive and open to discussing and finding mutual solutions to difficulties?
- 13.** Finally, does the school emphasise competitive spirit and achievement, or does it focus more on collaboration and the wellbeing and friendships of the children and teachers?

*Things not going well at school?* Institutions may be reluctant to make changes or take action when children experience difficulties at school. They are generally (and very understandably, I think) more disposed to either put it onto the individuals concerned or—if the issue is not one that impacts others very much—minimise any problems.

The school, therefore, (though there may be exceptions!) is rather unlikely to respond to your concerns with, ‘Thanks so much for pointing it out. Gosh, it does start to look like this problem is endemic to our community (if not our entire social system), so I guess we’ll need to address it as a structural issue’. Hm.

But, no...



Hope your week  
gets better, Fuzzy.



# Chapter 6

## Food

### *Joy and sustenance.*

How can a thing so necessary to our existence and potentially so pleasurable, at times become so *complicated*?

In times of plenty when nutritious food is abundantly available to us, things like being relaxed, experiencing simple enjoyment, and feeling at home in one's body, become key ingredients to a well-rounded diet.

## Do...

- 1.** Be aware about allergies, keep an eye on your child's overall health and wellbeing (if they look pale, and/or often have a runny nose, nosebleeds, tummy pains, or other symptoms). You could try experimentally removing things from their diet if you think they may have a negative impact.
- 2.** Provide healthy and regular meals. Good physical sustenance is fundamental to emotional well-being, especially for those who can be extremely sensitive to discomfort.
- 3.** Many people have found that there are times when supplementing a healthy diet with certain minerals, vitamins or tonics can be beneficial.
- 4.** Drink water, not soft drinks! Sugar and additives, especially in drinks, are very overstimulating, besides being bad for your

*Vitamins and supplements.* There is a lot of literature available on this – and it certainly makes sense that deficiencies can contribute to physical and psychological stress. You can observe through trying them if your child benefits from certain supplements.

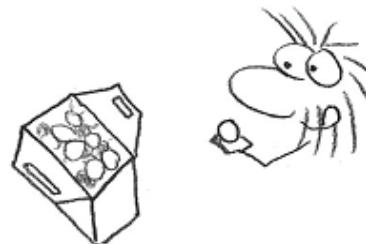
Having said that, if supplementing is done obsessively or taken to excess, and certainly if it's expected to be some kind of panacea, I think it could have a negative impact both on the emotional equilibrium of the parents and on the family budget.

teeth. You might observe your child go completely wild and overexcited for a bit, then suddenly all pale and floppy.

5. Give a few minutes warning before meals (or anything else that will require changing activity).

6. Try to eat healthily and regularly, and together. If your child gets bad-tempered, ask yourself if it's nearly a meal-time (many kids can burn up their fuel, seemingly almost completely, and suddenly go completely pale and feel awful... at which point it is time for some proper food, quick!).

7. Try to always have fresh fruit and water available, accessible for busy children to grab. Also other healthy snacks are an option (though maybe nothing too substantial if you don't want to risk ruining mealtimes). This is not to say you have to always avoid unhealthy foods, in fact I would highly recommend fun outings and ice-creams, or other delicious treats when enjoying yourselves together.



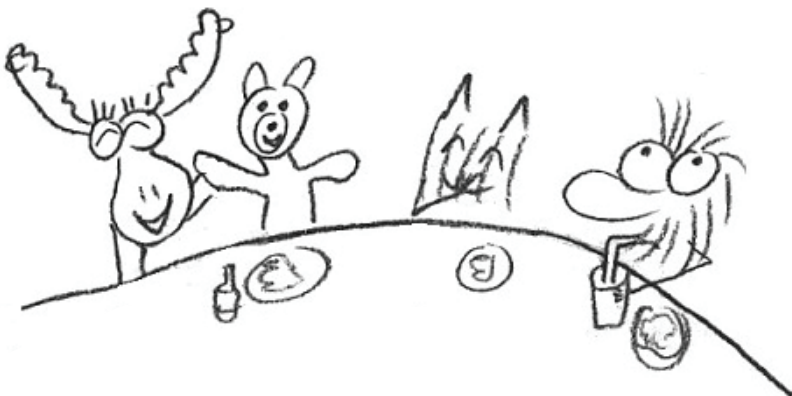
**8.** Provide regular meals and a pleasant environment, make sure you yourselves sit down to eat at every meal, and enjoy a chat together. Often at breakfast we look at books or make up jokes and stories. We regularly read books together at table, though I realise that's not for everyone. However no phones are allowed, especially not my own, as that's really not respectful to the people you're with (be they adults or children).

**9.** Serve things separately as far as possible, as that can really help. It can also help putting serving plates out in the centre of the table so people can help themselves to more if they like (if your children are too small to serve themselves, put small portions on their plates ONLY of the foods you are sure they like).

**10.** If your child really resists sitting up at meals, just sit yourself down and enjoy the meal anyway, while not providing any snacks between meals beyond fruit. However if that doesn't work after a few days (not wanting of course to starve your child!), just go for *whatever works*, making as little issue out of it as possible while continuing to model enjoyment and pleasant mealtimes for yourself.

**11.** If your children have trouble eating (and particularly with eating certain foods, like any vegetables for example), you could try using some silly and light-hearted games.

**12.** Consider introducing some basic rules for mealtimes. Keep them brief and relevant to everyone.





*Silly mealtime games.* Here are two we made up.

*'What's in the mouthful?'* In this game each person takes it in turns to take a forkful containing two or three (or even just one) of the things on their plate. While they do this, the other players look away or close their eyes. Once the person chosen has a full mouth, they keep it closed, and the others open their eyes and have to guess what's in there. 'Is it broccoli?', 'Is it chicken?' Nods and shakes of the head show whether the guess was right or not. A turn of the hand and raised eyebrows mean, 'You haven't guessed everything yet!' Once it's all been correctly guessed, that mouthful goes down and it's the next person's turn.

*'Food party!'* You make the food on the kid's speak in silly voices. The idea is, the different bits of food all really want to join the 'party in the tummy' where all the food that's already gone down is having *sooo* much fun! There's even a crazy helter-skelter slide that takes you there once you've been swallowed, ('*Wabee-ee!*') Just be really careful not to do this too realistically with kids who feel very compassionately towards their food.

This isn't at all to say you have to play silly games all the time at meals. But, used occasionally, they're ways to be focused on having fun together, rather than on what you're eating or where you are.

The idea is to put on *no* pressure whatsoever to eat, but to provide plenty of opportunities. It also reinforces the idea that mealtimes and eating are pleasant – times we really enjoy.

## Don't...

1. Don't put any pressure on your baby or child to eat, as this can have the effect of triggering their natural counterwill\*. And once that has happened, everything will become *much* harder.

2. Don't try and persuade your child into eating things they don't like (they may have issues with textures, smell, etc.), just say, 'Eat whatever you can'. You can gently suggest keeping quiet about the things that aren't liked as much, so as not to hurt the cook's feelings.

Oh, blech!  
Blech, blech, blech!



*Mealtime rules* will vary from family to family. The best thing is to stick to the absolute essentials and make it, as far as possible, collaborative. If people feel ownership, and see reasons for things, they are far happier about rules and more likely to stick to them.

We currently have three rules at mealtimes:

- a) Everyone has to stay at the table for at least ten minutes (this was to counter the inclination of the children, when in the middle of some gripping game, to guzzle their food in three seconds flat – refusing seconds, only to be hungry again an hour later).
- b) If anyone is finding the noise level is too much and getting on their nerves, they can propose a '3 minute silence' (using the egg timer). I've found it's amazing how you can really taste and enjoy your food during that lovely silence!
- c) The final (and I think most important) rule is that you don't moan or criticise the food, as unfortunately it's quite likely that the cook will get upset, on occasion even bursting into tears, and the mealtime will be ruined for everyone. If you find you can't eat the food, don't. Later – but only later (if your child can handle the waiting) – you can have some toast or cereal).

\**Counterwill* is an attribute of human behavior which has the function of protecting personal boundaries and enabling individuation. It's been described as 'having a will in reaction to the will of others'.

(Gordon Neufeld, developmental psychologist, has brought public awareness to this aspect of human nature, though first studies were done on this topic by Austrian psychoanalyst Otto Rank).



# Chapter 7

## Health, Hygiene & Fitness

### *Feeling well.*

Emotional regulation and the ability to introspect (be aware of what is happening in our bodies) are dependent upon feeling comfortable and relaxed in one's body and environment. Health isn't just about avoiding illness; it's about being *well*.

### Do...

1. Give and receive head and shoulder massages, if enjoyed.
2. Try some yoga, or dance, as this can be beneficial to both physical and emotion health, if your child likes it.
3. Be aware that any resistance when washing, showering, cleaning teeth etc. could be due to sensory issues (water too cold? Toothpaste tastes unbearable? Soap getting too close to the eyes?). Do whatever you can to make the experience more pleasant.
4. Regulate your child's bathing and showering around when and how they want to do it. They may enjoy a deep, bubbly bath with loads of toys in once every few days, rather than a shallow, functional one every evening.

### Therapy

5. If you feel unable to adequately support your child's mental and emotional health on your own, consider a therapist. Sessions can be either online or in your area. Make sure they are registered with a regulatory body in your country.

Unless you are going specifically for diagnosis and medication, I'd personally recommend looking for therapists who are experienced in *trauma* and *healing trauma* and know a lot about *highly sensitive people* (i.e. don't limit yourself to those who are experts primarily in autism or neurological disorders).

*The aim of therapy.* You child should gradually be made to feel accepted, approved of, validated and safe. Through a trusting connection with a therapist, they can come to terms with (and gradually reduce) their feelings of anger, pain, anxiety, and insecurity in the world.

A children's therapist should therefore be someone who listens and observes well (children's play, actions and body language usually speak far louder than words) and who can assist in forming those secure foundations of trust and belonging which will help your child feel better about themselves and the world.

If, instead of this, your child's therapist considers their biggest task to be 'improving' any outward behaviours (such as eye contact, for example), I would advise looking for someone else.

- 6.** Start with an informal chat, just you and the therapist, so you can test the ground. Look for empathy, genuinity, flexibility and kindness. Pay attention to how they speak and how you come away feeling. Look for someone who examines the environment and circumstances, and adaptation to everyone's needs.
- 7.** Ask about what materials they use and whose philosophy or techniques they adopt. Avoid anyone who uses coercive techniques, or ones that focus first and foremost on changing your child's behaviour. So some degree of non-conformism and open-mindedness would definitely not go amiss.
- 8.** Make an appointment for the therapist and your child to tentatively meet each other to see if they both get a good feeling. Making an appointment with a therapist should be done with the child's knowledge and ideally, their consent.



*'Is there something wrong with me?'* Very great care must be taken not to give your child the impression *they* are the problem. That's why I'd recommend therapy only if you feel there's no-one else in their lives able to give your child the necessary emotional support.

Unfortunately even the act of taking a child to a 'doctor' implies there's something wrong with them, thereby lowering their self-esteem and all-too-often increasing their distrust and withdrawal. This is no one's fault, it is rather a cultural bias (anyone with 'problems' tends to be stigmatised). However, this sad reality means any therapy or proposals about therapy have to be very delicately, carefully and sensitively done.

*When to give up, or change.* How is your child doing once they are doing sessions? Do they look happier and calmer? Or are they fearful and tense? Are they withdrawing? Trust your instinct on this. Don't feel obliged to pursue something your gut tells you isn't working.

If your child is generally quite expressive with you, they may tell you outright whether they like it and if they want to do more. If you think it's benefitting them but they don't agree, perhaps (if it will not stress them too much to do so) suggest to them doing just a couple more sessions. If you encounter great resistance to this idea, *let it go*.

If their reaction is milder, however, you can try telling them that if they still feel the same way after, say, one, or two, or three more sessions (however many you think appropriate), then you promise they won't have to do it anymore.

Note: You *must* then faithfully keep your promise. Any attempts at further persuasion will be disastrous. They'll be much more disposed to try a different therapist, later on, if you now gracefully let it go without a fight (they will trust you more).

**9.** Once your child has started therapy, observe closely whether they seem happy (or are they pale and ambivalent?) after sessions.

**10.** Give your child opportunities to talk to you, rather than quizzing them about how their therapy went. Go for a walk together, or do a puzzle or colouring together. In companionable silence. Sit by their bed while they fall asleep. In short, *be there* when they begin with related thought processes and questions.

## Medication

**11.** Keep any medication on as low a dosage as possible, trying only one thing at a time, and only using it if absolutely necessary.

**12.** Avoid both long-term use and increasing the dosage if the effects seem to lessen.

**13.** Inform yourself thoroughly about any medication you are thinking of giving to your child. Carefully document usage and how your child is responding.

## Hospital

**14.** If your child needs to go into hospital for any reason, and in particular if they need to stay overnight, make sure you let the staff know that your child is autistic.

**15.** Emphasise the importance of you or another close family member staying with your child during medical procedures and visits to hospital or to a doctor's.

For more information on *medication* I'd advise starting with consulting the works of Temple Grandin, Lorna Wing, and Tony Attwood on the subject. Their suggestions about taking medications are all based directly upon their own personal and professional experiences and personally, I found them extremely practical and helpful. Recommended books are in the Reading List at the end of this book.

**16.** Ask to be informed about what is happening and what is going to happen. Then you can give the necessary information in an understandable and palatable way to your child.

**17.** Focus on keeping your child feeling safe and reassured to the greatest extent possible (in particular when they're going under a general anaesthetic).

**18.** These are reasonable demands, so be insistent if there's any resistance about them being met.

## Don't...

### Learning to use the toilet

**1.** Don't say 'ew' or 'yick' when you change your baby's nappy/diaper. It's better to coo, and smile, and make some eye contact; maybe sing or chat to your baby. Changing should be a positive and caring experience; an opportunity to enjoy the love and intimacy between you.

**2.** Don't buy a potty straight away, unless you are camping or the toilet is far away (i.e. purely practical reasons); instead try investing in a comfy, padded reducer seat for your toilet.

**3.** Don't put a lot of pressure on your child to use the toilet instead of nappies/diapers, the best motivator is to take every

*Using the toilet vs using a potty.* I realise that experiences may differ on this. I've observed how in our family the children generally seem to want to copy what the grown ups do, and the fact is they see us using the toilet not a potty (me not actually being willing to lead by example on this one).



*It just ain't working!* If your child won't poo except in a nappy even when older, you could try gradually making the change.

- a) Bring them into the bathroom while they go into a nappy.
- b) (If the previous step goes well), try encouraging them to sit on the toilet while doing this – still in the nappy.
- c) (If the previous step goes well), make the nappy gradually looser and looser, until it is just draped on the seat.

At any step, if there is resistance, try just going back a step or two and start again (this is a suggestion that I read in Lorna Wing's book *The Autistic Spectrum*: it sounds to me like a very good and sensible strategy, and clearly one which was often successful).

Another strategy, which worked for friends of ours, is to spread some newspaper on the bathroom floor and let your child stand over those (it might be a question of posture, and being used to eliminating standing up).

Hard as it is, try not to ever show any frustration or annoyance (*Aarrgh!*), and certainly to never show disgust or disapproval. It's terribly important not to evoke shame around this issue, as this has the potential to create problems, including quite serious medical ones, later on.

opportunity to have your child not wear one (does your kitchen have tiles, not a carpet?). They will quickly become aware of when they go, and will observe how the grown-ups do it.

## Fitness and sports

4. Don't pressurise your child into doing structured sports—particularly competitive ones and/or team sports—if your child has no explicit wish to do them. It's much more important to give them enough freedom and time to explore and experiment.

More suggestions for living the sort of *active, healthy and relaxed life* that leads to physical fitness are given in *Out and About* and *At Home* (Chapters 1 & 2).

*Alternatives to sport.* You can along with your child's interests in a gentler environment. E.g. is your kid interested in climbing? Instead of taking them to a rock-climbing course, try taking them to somewhere quiet with suitable walls, rocks, or trees, and let them roam. Bring your book and sit with your back to them. Refrain from giving suggestions or instruction. Bring something calming, like some chamomile tea, so you don't end up with no nails.

*Physical health and fitness.* In an ideal world, we would spend some time outside every day. And on beautiful days when you (or another willing family member) are free, real outings are the best way in the world for keeping fit. Woods, parks, beaches – if you are lucky enough to have any of those accessible. And having a dog (*only* if your life permits), can be great for forcing us all out-of-doors at intervals.

Activities could include walking, biking (if possible), canoeing, camping, swimming (or paddling), gardening, taking photos out-of-doors, observing plants, flowers and wildlife.

If your child isn't keen on the outdoors, experiment with things like 'walking to the shop to get a juice', or 'a piggy-back to the park to go on the see-saw'. Often it's the way we frame things that makes all the difference. (For example, seasoned parents know you should never suggest to a child, 'Let's go for a walk'. Instead you say, 'Let's go on an adventure – and take a picnic!')

And, having said all this, the best thing you can possibly do for your child to enjoy being active and out-of-doors is to be relaxed about it, while clearly loving doing those things yourself. If you don't feel that way, chances are your kids won't either. I believe that's why we need a community and other trusted adults and mentors around. Something we unfortunately, to the great detriment and exhaustion of parents, very rarely have.



Gleefully glad  
to be me!



# Chapter 8

## Physical contact & emotions

### *Energy in motion.*

Autistic children are extraordinarily sensitive to 'energy in motion' (or 'emotion'). Many of their difficulties with expressing themselves to others, whether physically or emotionally, are down to simply being overwhelmed – both by their own emotions, and other people's.

### Do...

- 1.** Give unlimited access to physical affection. This is essential for small children and infants, though important for all ages, depending on demand. Note however your child may not be comfortable with *unsolicited* shows of affection. Let them take the lead if you are uncertain or if they show any signs of discomfort.
- 2.** Try making affectionate animal noises (purring for example) when your child spontaneously caresses and hugs you. It can be sweet and funny, while being both encouraging and unthreatening.
- 3.** Try nose-touching (touching your noses together) if your child is not keen on kisses.
- 4.** Leave your child in peace when you sense they are withdrawing (by this I do *not* mean banishing them, or giving them 'time out'!) Gently tell them that you are available when they need you, and if possible stay within sight, physically present but getting on with your daily tasks e.g. cooking, reading, working, or whatever.

*Emotional withdrawal?* No need to bother your child with any questions or demands right now. You could make one or two gentle and unobtrusive gestures like putting a drink or snack to hand, or tucking a blanket around them if it's cold.

When they slowly start to look like they are feeling a bit better, perhaps offer to read to them, or to accompany or help them in any preferred game. If they refuse, make it clear that's okay too and that you're there for them whenever they need you.

5. Try hair-brushing and massages, as both giving and receiving can be really companionable and pleasurable. If your child doesn't like being touched, you could try some non-threatening things e.g. perhaps they like styling your hair while you read to them or in front of the telly. I think it is much less scary for them this way as a) they are the proactive one, fully in control of the situation and b) your attention is not focused on them.
6. Listen carefully if your child ever does feel like talking to you about their feelings. Show real interest. Refrain from offering your opinion unless it is asked for.
7. When talking about emotions, always make it clear to your child that you consider it legitimate and perfectly normal to feel the way they do in the circumstances.
8. Carefully, in moments when your child seems receptive, and only if it feels really natural and right (and while keeping a very open mind), you could try to help your child identify their own more difficult emotions. Try asking them gently and flexibly what feels like (also physically). Stop talking if they ask you to, or if they're looking blank or defensive – observe their body language towards you, e.g. if they are hunched, withdrawn, or turned away.
9. Be understanding with your child when they show strong emotions. Try to ask yourself what the child's intentions were before getting annoyed, or what stimulus they might be responding to.

*Emotions are information.* There are *always* legitimate reasons for feelings, even when the 'why' of them is not fully known or understood. Therefore, denying or judging others' feelings is extremely counter-productive. You can't change how they feel simply by thinking it's unreasonable.

For a more systematic approach to *dealing with difficult emotions* (both for yourself and for your child), I'd highly recommend trying out Tara Brach's technique, 'RAIN' (as described in her book *Radical Compassion*).

Say you feel a difficult, puzzling, or strong emotion. On realising that, try following these steps, taking plenty of time over them:

**R.** *Recognise* what is going on for you. ('Ah, hello feeling!')

**A.** *Allow* the experience to be there, Just as it is. ('Hey, feeling, it's okay, you can come in now...')

**I.** *Investigate* with interest and care. (Here you take a look inside yourself, with curiosity – how does it feel? In your body, etc.)

**N.** *Nurture* yourself with self-compassion. (I say at this point, to myself or to another who I'm guiding through it, 'At this point you just hold and love yourself – as though you were someone you love very much indeed!')

*Deeper reasons.* Maybe meltdowns are rarely truly about the thing that apparently caused them, like being given food you dislike or having to leave the house. Isn't it more likely to be about deeper things e.g. not feeling safe, sensing stress or conflict, lack of control, habitually not being informed or consulted, or feeling misunderstood/judged?

*Affective empathy.* It is no coincidence that your child suddenly becomes more demanding and impossible in exactly the moment when everyone is getting stressed, or worried, or hurrying. Being sensitive, your child is probably sensing and reproducing the emotions that are circulating around them.



**10.** Make it clear to your child that it's fine if they do not wish to accept or return gestures of affection from adults. Support them in pre-empting and avoiding situations like these.

**11.** When there has been a misunderstanding and someone feels hurt or annoyed, focus entirely on making things better, and making amends if possible. (Empty, sullen 'sorries' have extremely limited value, in my view).

**12.** You could, if appropriate, make some brief and neutral suggestions about how to make amends when you have upset someone – e.g. helping pick up things that got dropped on the floor, or asking someone who got hurt 'are you okay?' But keep in mind you are making mild, gentle (even humorous) suggestions, and absolutely *never* enforcing anything. If the child is too angry or upset to follow through on them, never mind.

*Why do I sometimes feel angry when I know I've upset someone?*

It might be worth mentioning, and to your child too (if relevant), that we can have an angry reaction when we realise we've hurt someone. I know I sometimes do, irrational as it may seem!

Perhaps this is because we feel hurt ourselves, by the incident? Humans are essentially very empathetic creatures.

And, because we live in a culture which emphasises blame and punishment—which has the knock-on effect of encouraging and priming people in the gentle art of self-exoneration—I then naturally require an object to direct my 'righteous' anger at. Who? Ah, the person I've hurt, of course (to my puzzlement and consternation, now I've analysed it!)

*Modelling being forgiving and understanding* is what's important. Each time *you* do this, it becomes far more likely your child will follow suit. So be careful to strenuously avoid making character judgements, laying blame, or holding grudges.



## Don't...

**1.** Don't shush your baby or child when they cry. It's best not to teach young children that feelings should be smothered, and that showing you're sad is not okay. Much better to rock gently, sing, say encouraging things like, 'There there, I'm here love, aww poor one', and so on.

*Showing empathy.* If it's obvious what's upsetting your infant or child, you might say something like 'Gosh, that was a big bump', or, 'It's really upsetting when things don't work out the way they were meant to.'

Try to not mind what people think. In any case, acting because of 'what people might think' is not really advisable, as your baby will most likely sense the tension and yell more.





2. Don't physically restrain. Use every other means available, starting with respectful requests and explanations about things, in carefully chosen moments. These will bear fruit, so be patient.
3. Don't grab or yank, or force hold, outside situations that are genuinely life-threatening. Even in those, afterwards you'll need to give a lot of comfort to your child, and show deep regret about it. If you do have to explain, stick to things like, 'I was really scared! I thought you were going to get hurt!' Don't explain to them why 'it was necessary'. Reality is subjective. You only know about your own. If you have to use that word, say, 'To me it seemed necessary in that moment.'
4. Don't be hurt and offended if your child doesn't respond to your emotional needs – or respond at all if their mind is elsewhere.

*Physical restraint.* The price you will pay, if you have no choice but to use force, is the erosion of your child's trust in you, accompanied by their physical withdrawal from you.

If you think your child may seriously harm others or themselves, and you feel unable to cope with it calmly and preventatively (e.g. by providing alternative and less harmful outlets for explosive feelings), then a) look up any helplines that can be called in moments of crisis, and b) discover what welfare and health services there are locally.

In extremis, finding a counsellor or therapist can be a good idea. See Chapter 7 for more on this.





*Delving for information, and asking questions.*

The effect can be to make the child clam up where they might have later spontaneously, and in their own way, given you information.

Besides which, it's very unlikely they'll know what you're getting at and even more improbable they'll feel like talking about and analysing social situations and their feelings about them. It also indicates that you are worried/anxious, which increases the pressure to perform. say nothing, or lie (if they are able).

5. Don't ask your child a lot of questions about people, situations and feelings (i.e. delve).

## On anger

6. Don't respond in an angry or negating way to emotional outbursts – instead try to a) remove distressing factors, and b) understand the cause.
7. Don't respond to anger with censure, for example requests to 'calm down', 'behave', or to apply self-control.

*Where does anger come from?* Anger always comes out of feelings of pain and hurt (including, for example, loss, rejection, defenselessness, and feeling misunderstood). This is useful to remember in difficult moments. It's very important that your child also knows that their pain and frustration *always* has a legitimate cause (even when we don't necessarily know what it is).

Once accepted/validated, anger can be processed. If one's anger and outrage is never accepted in this way, it will gradually internalise and manifest itself in withdrawal and destructive feelings towards oneself and/or the world.

*Escalation of unexpressed anger.* If today your child is unable to diffuse their feelings of anger through expression, it becomes a lot more likely those feelings will escalate.

In other words, you may be dealing today with yelling, a mess on the floor, or a few thrown cushions. Or, if you categorically prevent and forbid that (without helping your child find other effective ways of expressing their anger and pain), you may be dealing with broken furniture, violence, or self-harm and even suicidal thoughts when your child is a few years older.

*What if my child's anger is directed at me?* As the primary carer, even if you are really close to your child and they trust you, angry feelings may be directed at you. Don't forget you are the closest one they have. Getting on the defensive isn't going to help much.

Plus, I'm afraid that as tempting as it is to ask your child (for example), 'Why? *Why?*', I think it does a great deal more harm than good. Chances are your guess is as good as theirs, and the message your child receives is, 'What is *wrong* with you?' – as well as that they are too much for you. (Yup. Been there, done that...)

8. Don't take it personally if your child's anger is directed at you. Listen and observe (without judging or disapproving), try to understand, keeping in mind that anger comes from hurt.
9. Don't deny the outlet of angry feelings in your presence (or failing that, with another trusted adult figure in their lives). This could do a great deal of harm, as your child could easily direct the hurt and anger onto themselves instead.



*Ways to help your child with anger.* Start by making it clear that you're not going to judge them or stop loving them just because they're raging and rampaging. Let them know you recognise their feelings as legitimate.

Then, you need to help find effective and creative ways in which the anger can be adequately expressed. If you manage to dedicate some time to doing this regularly, then the anger and frustration is less likely to burst out so often in really inconvenient moments.

*What are those effective and creative ways?* It depends on the individuals and the situation, but as a rule they must be things that *work for them* and are *not harmful* either to themselves or others. Some examples could include:

- a) Pillow fights.
- b) Ripping up old sheets.
- c) Singing or rapping.
- d) Playing the drums or another musical instrument (for slightly older kids).
- e) Drawing pictures of how angry you are (yes, to my amazement this actually can work!)
- f) Dancing wildly round the living room to *The Clash*.
- g) Running and yelling like crazy, in a field or on the beach.
- h) Flinging stones as far as you can into the sea or a lake.

And basically, anything else you can think of, that works and doesn't hurt.

As this process unfolds, over time (if other circumstances are right for it), you will be able to see your child's anger gradually transforming itself into grief, and then slowly, over time, dissipating. This process can be called 'the healing process'.

If you do this, you must get some *emotional support yourself*. Perhaps from your partner, mother, sister, best friend? Or, if none of those are possible (as it is important that they will not judge, or disapprove of, either you or your child), see if you can find a parents' support group and/or a therapist. Information on identifying a suitable therapist can be found in Chapter 7. Online groups can also be supportive (more on this in Chapter 11).

*During this healing process*, it may still at times happen that your child suddenly feels really emotional for no apparent reason. If they now seem approachable and more trusting of you, you can tentatively suggest trying various things that might help them feel better (based on knowing them, observing, and past experience), making suggestions and maybe trying out different things together.

Maybe a head massage, or the floppy-legs yoga exercise (see Chapter 7), or else making up a story, or looking out of the window together imagining if there are people on other planets. Anything, really. The important thing is to wind up each time with acceptance, friendship and understanding between you.

**10.** Don't be tempted to offer 'positive reinforcements' for the non-expression of emotion, even if their emotion is sadness or anger. If your child gets weepy at bedtime, follow the steps in Chapter 9, *Bedtime and Sleep*.

## On affection and healing

**11.** Don't force, coerce or pressurise into making affectionate or loving gestures. Be aware that your child may not be able to respond to your emotions (e.g. they may resist your embraces, or not provide comfort to you when you feel you need it).

**12.** Don't despair if your child seems not to be happy, cheerful or carefree, much of the time. Just closely observe what makes them feel better (look for the smile and the shining eyes), and what makes them worse (look for the downcast eyes, pale anxious face and hunched shoulders). Make a list. For a while, try to focus on only doing the things that make them feel good, avoiding the bad things.

**13.** Don't say, 'It's nothing', or, 'No need to make a fuss', when your child hurts themselves.



*Affectionate gestures, and patience.* You can't pressurise someone into feeling something they don't – emotions don't work that way. I think we are all familiar with the feeling we've been given no choice in doing something, and suddenly it is the last thing on Earth we want to do!

So, with your autistic child, give them complete freedom around affectionate gestures and physical contact, while demonstrating your continuing respect and availability. Make overtures yourself only when you sense they are welcome. If you see they are *not* welcome, withdraw respectfully. (And, if you feel resentful or rejected, or just plain upset, those are very natural feelings but *not* ones you want to show your child. Perhaps talk to a friend or family member about it, and if those are not an option, try a therapist or counsellor.)

*Emotions are still information!* There is no such thing as 'negative' emotions, just ones that are harder to deal with – which are arguably often the ones containing the most valuable pieces of information.

There will be times when it's much harder to let your child express themselves. Strategies for dealing with this (and hopefully postponing the 'expression' part to a more convenient moment) can be found on p.33 under the title, 'Meltdown'.

But the more you follow these strategies, the less often you should find yourself in such crises. Your child will start feeling safer, feel 'held' and understood, and will therefore be experiencing lower levels of anxiety and/or frustration overall.

**14.** Don't lose sight of the big picture. Keep a log for yourself if that helps, so you can see how things are going over time (how often are meltdowns occurring? How often are you seeing your child carefree and happy, and for how long? How many full days are you managing without major setbacks? When setbacks do occur, how long do they last? And so on.).

*When your child has a physical hurt.* Try making sympathetic noises, giving a cuddle (if wanted) and seeing if there's anything you can do to make it better.

If your child refuses help or contact, stay close by but unobtrusive, making it clear you are there as soon as you're needed.

You can gently repeat at intervals, 'I'm right here when you need me.' If you are holding them, e.g. on your knee, and you're in a public place, try to keep your child's back to any interested or sympathetic onlookers. You could discreetly shake your head at those people to try and get them to move on.

Some gestures can make little hurts better. Some ice, or a plaster? Sometimes little 'medicines' like this work more as an effective placebo than as a direct cure. Or 'kissing it better' for small children.

*Healing: Contraction and expansion.* Peter Levine and Besel Van Der Kolk (see Reading List) both talk about the cyclical nature of human processes, i.e. when resolving and healing trauma. They describe how 'expansion' (starting to feel good and confident again) is commonly followed by a natural 'contraction', often caused by some minor setback (oh no! Actually everything is awful, how could I have trusted it to be good?).

This pendulum effect is standard – so it's important not to see every setback as complete disaster. I have a strong tendency, just like my son, to be 'all or nothing'. Things are either absolutely wonderful or totally awful. That means that there's a real danger of falling into abject despair over minor setbacks, which I can see does not do my family much good.

Reading these books has really helped me to get perspective on this, and to be calmer when things go wrong.



*A gradual approach.* If there are areas you know are really important for your child to be challenged in and to eventually develop a positive/proactive approach to, even though they seem to provoke anxiety in your child, then once your child becomes a bit more emotionally stable and positive, introduce those things/activities in small doses, in the most palatable way possible, and with plenty of the feel-good de-stress stuff in between.

Note: it can be useful to think of this as a process. If the overall direction is gradually towards more positive engagement, equilibrium and resilience, you're on the right track! It is absolutely normal that it might often seem like 'ten steps forward, nine back', or even at times that things have suddenly gone right back to awful again.

*Help in the healing process.* If you are not managing to deal with, and over time diminish your child's anger or grief, seek professional help.

**Do not feel you've failed.** It's not you – this is *hard!*

A professional therapist may help you greatly in dealing with it all constructively (see Chapter 7). Don't forget, you're acting as informal therapist for your child. Only with no backup, and no training!



## On withholding approval

**15.** Don't hold unspecified grudges or give off an aura of disapproval (or disappointment towards someone).

**16.** Don't poke fun at your children, or be even mildly disapproving, when they are exuberant, impassioned or wildly enthusiastic. Roll with it. Be enthusiastic too!



*Grudges and disapproval* are really confusing and upsetting to others, especially very sensitive individuals who are not adept at the social 'dance'. It makes them feel terrible without telling them what they can actually do about it.

Try instead simply saying how you feel 'I'm really tired', 'I get stressed when we have to hurry', 'I hate getting in so late to a dark cold house'. With no blaming anyone, and no argument (no-one can deny how you feel, after all), it's quite likely you'll be freely given some sympathy and help.

## On needing control

**17.** Don't fall into the belief that your child needs to always control external things in order to be happy.

**18.** Don't assume you can't ever make changes, either to fixed routines or to your overall way of life, because of your child's difficulties with dealing with new things.

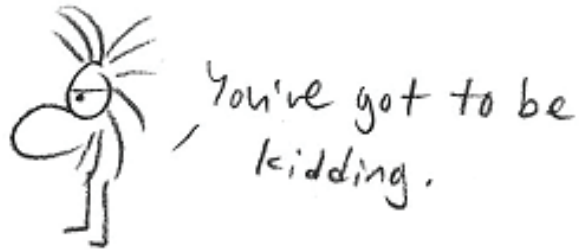
*Obsessive regimes and acting 'controlling'* are invariably down to an overall sensation of feeling lost in the world, and unsafe. We then cling to things that might bring some stability. Equally, we might fixate obsessively within a very limited and therefore manageable sphere, in order to block out the dangerous and unmanageable stuff as much as possible.

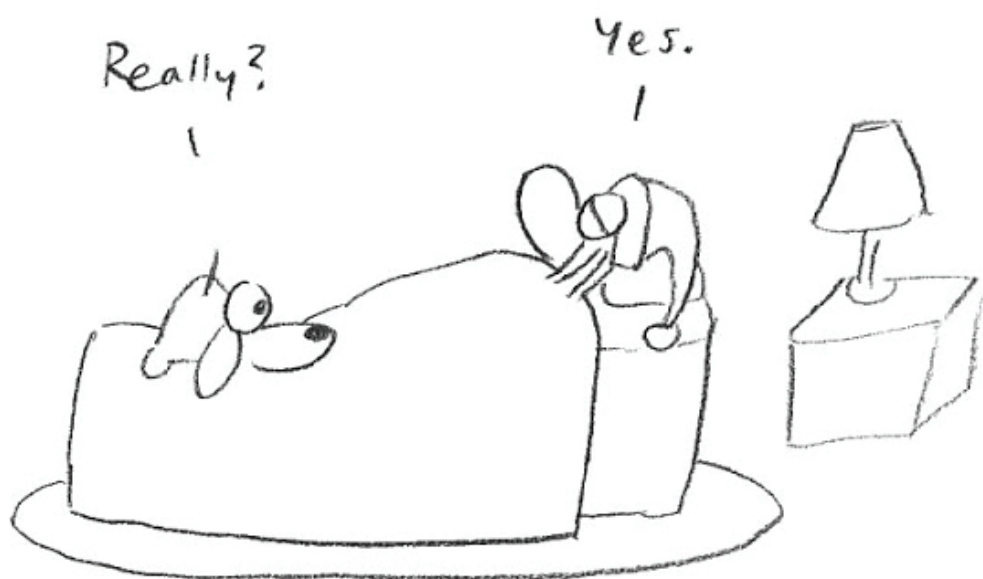
What we wish for is to eventually achieve *inner stability* through safe, loving connections and stable relationships with animate beings (as human beings it seems we find this is necessary for complete fulfilment). This is the foundation you are helping your child build, by being there for them and being understanding and accepting of them. Once any child has that foundation solidly built they are well equipped to manage pretty well in life, even in the face of change and adversity.

*Introducing change.* When thinking of making any changes, as parents we need to place a huge focus on our child's overall emotional wellbeing. We want them to feel safer, with less need to be anxious, not just externally but internally too. (Pretty much all the tips in this book aim to reduce anxiety and increase confidence and 'feeling safe' in the world.)

Once a child learns to feel safe within themselves they will be far more receptive to change.

*Considering siblings.* It's important to keep an eye on the rights of siblings when addressing burdensome routines and inflexibility.





# Chapter 9

## Bedtime and sleep

### *To bed, to bed...*

Parents are generally much keener on the idea of bedtime than children are. And autistic children can have particular issues around sleeping and bedtime. This is usually due to high levels of vigilance and anxiety which make it hard to relax.

Luckily, there are many ways the whole process can be made gentler and friendlier for the child. This is important, as having a good relationship with sleep is essential for a person's self-regulation, resilience and wellbeing.

### Do...

- 1.** If people say you shouldn't carry on having your babies sleeping in the same bed as you, as you're 'teaching them bad habits', try to take it lightly.
- 2.** In infancy, often the easiest sleeping arrangement is having a cot with one side taken off alongside the parents' bed – this way you can get to each other simply by rolling over, so it's less likely you'll hurt your back or get cross, or walk into the wall. In fact you don't even need to properly wake up, let alone get up.
- 3.** When your baby gets older and more agile, consider going straight on to a proper child's bed, with just a low barrier to prevent falling out. This way your child can climb in and out of their own bed (making them much happier about the whole

idea), and you can lie down next to them in their bed when reading or comforting. No more uncomfortable crouching over cribs or back-breaking acrobatics trying to get them in and out.

4. Try gentle yoga exercises, or massage, to calm and relax a child at bedtime.
5. Get ready for bed when everyone's still perky. If you wait too long, people tend to get over-tired and crotchety (and that includes the parents).

*Baby in the bed.* However, while you shouldn't let public opinion dictate to you on this, if it's really driving you crazy (or if you find yourself looking at your partner thinking 'do I remember you?'), try to think of some alternative solutions once your child is a bit older.

Could your Labrador's bed be moved into their bedroom so they have company, or could you place a comfy armchair next to their where you can sit for a while when they feel insecure or have a nightmare (it should be *very* comfy and equipped with a nice warm, soft blanket)?

Your child's room, if they sleep separately from you, should be close enough to easily hear if they cry or call out, even quietly. Leave the bedroom doors open and a night light on in the hallway.

*I want my bed back!* Most babies will graduate to their own beds quite happily in a year or two, and for those who don't, and continue to appear as if by magic in your bed every night, there is surely a good reason for it (see page 134 for a grandmother's wise advice). Maybe you could draw the line at them kicking you all night (literally – a bolster perhaps?)



*Preparing for bed.* Something that really works for us is, when reading a story (e.g. on the sofa in the living room), taking a break between chapters for changing into pyjamas, brushing teeth, etc. and then having the next chapter in bed. If you're watching a film, you could pause it and have an 'interval' for this purpose.

*Bedtime relaxation.* For a while, my son asked almost every evening for the following exercise: he would lie on his back on a soft blanket and try to make his limbs floppy and relaxed. I'd take first his feet in my hands and lift them a little off the ground, move them in small circles, and then wiggle and shake them gently for a while, then the same but with the arms and finally very gently lifting and moving the head a little way from side to side and gently massaging the neck (he often starts giggling then).

I'm not by any means saying this is for everyone, but you might find similar things that are really relaxing, feel good, and involve your child being fully in their body and trusting another person.

Follow your child's lead on what they enjoy, and follow their instructions when they say 'more', 'less', 'higher', or 'ow, stop!'

**6.** Look into using pressure for reassurance. Weighted blankets work for some, for others (thinking of a specific friend) a largish or weighted toy can be reassuring on the chest (hers was a furry cat – and now she has a real one!) There are also many weighted pillows and shaped cushions available.



# Don't...

- 1.** Don't, if you're not into it, make your baby sleep alone from an early age. People may not tell you this openly, but there's a lot of pressure on parents. We are often asked things like, 'So, is he in his own bedroom yet?', 'Is she sleeping in her cot?'. These questions can seem a little loaded, especially given the normal reactions when you respond. A 'yes' might evoke enthusiastic, approving reactions, while a 'no' may elicit a disappointed or even disapproving reaction.
- 2.** Try not to have too many toys in bedrooms, or keep them in a way that you and/or your child can put things away easily in cupboards or boxes.
- 3.** Try not to have screens or devices in bedrooms, if at all possible. Bedrooms, ideally, should be areas of peace – both of environment and of mind.
- 4.** Don't tiptoe around, close doors, and forbid visitors if your child or baby sleeps lightly, and has trouble going to sleep. Your baby can nap in their pram in the kitchen alongside you while you cook, play music, or work. If they wake, pick them up and carry them on your arm for a bit. It may sound counterintuitive, but sleeping well doesn't depend on silence – it depends on peace of mind and feeling safe, and therefore *wanting* to fall asleep, and stay asleep, when you're tired.



# Chapter 10

## Pregnancy and birth

Birth trauma is known to significantly increase the chances of babies and children developing developmental disorders later on, while 'in utero' distress due, for example, to exposure to stress hormones, puts them more at risk of suffering from anxiety and depression.

If you have autism in the family, there are things you can do to minimise risks – in pregnancy, during childbirth, and immediately after your baby is born.

The tips below may help to improve your own and your baby's experience of birth and reduce the chances of them (or you) suffering any avoidable distress or trauma.

### Do...

- 1.** Try to make sure your pregnancy is relaxed, calm, and passed in a way that is as joyful and stress-free as possible.
- 2.** If you feel stressed, unwell or unhappy, try to find ways that to alleviate this, enlisting others and keeping in mind the longer-term perspective whenever you consider your options.
- 3.** If you can, during pregnancy do some yoga for pregnant women. In particular, the breathing and articulation can make the difference between a good birth experience and a not-so-good one.
- 4.** If possible, arrange to have someone with you during the birth who knows how to support you in the breathing,



articulation and rocking. Ideally, you need someone loyal and able to be assertive.

**5.** Go to the hospital while you are pregnant (even if you are planning a home birth, it can be good to find out about the local hospital and procedures just in case you did happen to be brought there, for whatever reason). Meet the midwives, ask about standard procedures, and who you're likely to get at different times. Some suggestions about questions to ask are given below.

**6.** Read up about other women's experiences, and write a short description of your own ideal birth (your 'birth plan'). See if you can find a way to have your midwife/s read it.

**7.** When the moment arrives, bring your favourite pillow and blanket to hospital with you. It can be surprisingly reassuring having a 'piece of home'.

**8.** Have plenty of drinking water on hand, and possibly even some light snacks in case you need them to keep your strength up.

**9.** Be prepared to have painkiller if you need it. Don't feel you have to be brave, this is not the moment. Personally, I found it very reassuring knowing there was a ginormous painkiller available if I felt the need for it.

**10.** If you do need a caesarian, an epidural, inducing and/or other interventions during birth, it's totally fine. All births are different. Some births do require far more intervention than others. There are women who easily give natural birth to their first four children, only to require medical interventions when giving birth to the fifth'

'Articulation', in my experience, means saying, 'Aaaaah' loudly and deeply on your out-breath. I know it sounds very weird, but it really helped me... maybe because it stopped me from screeching, 'Eeek!' and forgetting to breathe altogether?

*Visiting the hospital, and meeting maternity ward staff.* While they may have little time for you in a public hospital, this may make for more understanding between you and the people who are caring for you, and more confidence in them, and therefore an easier birth.

Make sure you *bring a notepad* along to write down notes and answers to your questions.

If you're not satisfied, look for alternatives. Ask at your yoga class (if you go to one), and also ask any friends who've given birth recently for their advice.

### *Some important questions are...*

- ✦ Can I meet any of the midwives who will be on shift around my expected birth date? (If it's a private hospital, you can probably choose the midwife you wish to assist you.)
- ✦ Is inducing done only if the mother or baby's health are seriously at risk?
- ✦ Are epidurals given only on my explicit request, and in consultation with me?
- ✦ Is my chosen companion allowed to stay with me the whole time?
- ✦ Will any medication (inducing etc.) be given to me without my explicit consent (Or that of my companion if I'm unable)?
- ✦ Can I move around during labour and birth, or will I be obliged to lie on my back on a bed?
- ✦ After birth, is my baby allowed to stay with me immediately and from then on (also during the night), or will they be taken away and if so, for how long exactly and for what purpose?

*Your own midwife.* The ideal, though unfortunately very rare, is to have one-to-one care. This would mean being followed and assisted by one midwife throughout your whole pregnancy and birth – preferably someone you know, like and trust.

*When to induce?* When you're induced it becomes more likely you'll need an epidural, and statistics show that the odds of birth by emergency caesarean also go up.

Sometimes, unbelievably enough, contractions go away during a natural birth for long enough for the mother to actually have a rest or even a short sleep – which might be much better for mother and baby than being induced at that point.

However, if there are clearly strong medical grounds for being induced (i.e. if your or your baby's health are at risk), then the case is different.

Being induced can significantly change the birth experience, as contractions are more likely to be erratic, and can start off significantly stronger than the first stage of contractions during a natural birth (a gradual build-up, which you have time to get used to, generally makes for arriving at the actual birth in a far better condition emotionally and physically).

It seems likely it could also make quite a big difference to the baby's experience of birth, as in a natural birth the mother takes the hormonal cues from her unborn baby.

Therefore, if you feel under any pressure by the medical staff to be induced, perhaps your companion can be primed beforehand to check that there are good reasons for this.

Once you're in labour, if you are getting a bad feeling about your midwife—if they are not friendly and make you feel stressed—try to insist on getting someone different, enlisting your partner or friend's help in this. (This is why it can be so important to meet the key staff in your local/chosen hospital beforehand. Once you're in labour, this is just the kind of stress you really don't need.)

**11.** After your baby is born, insist they sleep together with you in the hospital, not in a cot and definitely not in a different room. This way you're able to cuddle, hold and feed them when you wish to.

**12.** Use a sling/baby carrier (often a simple long cloth is the best), as this can soothe your baby wonderfully when they are stressed, grouchy or tired.

**13.** If your list of baby equipment to buy includes a playpen, hold on that. For learning positive exploration of our world,

*Separation of mother and baby.* I think it is hard to imagine how traumatic this first separation from the mother might be for a newborn infant. It should only ever be done when there are serious medical issues involved.

The stress induced from separation, in particular if prolonged, can impact the healthy development of a newborn's neurological processes. (For more information about this, see Sue Gerhardt's book *Why Love Matters: How Affection Shapes a Baby's Brain*.)

*Sleeping together.* Very small babies are unable to move their own bodies much, and they need some moving around for comfort, exercise, and to aid digestion. They also need body contact to feel peaceful, warm, cared for and loved.

If you are sleeping next to your baby, you are sensitive to their movements, breathing and sounds they make, so you are more likely to respond instinctively with providing what they need. You also don't have to get out of bed and stumble around in the dark, cursing and tripping over things, in order to get to your baby's cot. If anyone talks to you about the dreadful consequences of 'spoiling' your newborn baby, you can be polite, but discreetly leave their advice on the doorstep when entering parenthood.

*Will I squash him/her?* Unless you are taking sleeping pills, the answer is, no, you won't. It lies deep in the instinct of a mother not to lie on her baby.

starting inside the home, playpens are counter-productive. In fact, they can bring a child to feel that very isolation and alienation which we are trying to guard against.

**14.** Encourage your partner and other close family members and friends to take turns, to give your back a rest and so your baby gets used to being soothed by others, not just you.

**15.** Resist any pressure to put your baby on a feeding regime. Babies who later turn out to be on the autistic spectrum very often, and more extensively than babies usually do, use feeding for other purposes besides just getting milk. The sucking helps their digestion (they may be colicky), and the contact and warmth of being held against your body makes them feel secure and safe.

*Feeding regimes.* If you've read or been told that a feeding regime is advised as being beneficial either to you or your baby (or both), you might want to consider it carefully. While it can make sense from a nutritional point of view, withholding can mean a lot of emotional turmoil for both mother and baby. There are other purposes to feeding (for love, warmth, reassurance, comfort and closeness).

Also, I believe among the most problematic concepts to teach to a new baby (in particular one with autistic tendencies) is that they have *no control over their own fate*. Someone else is running the show, and nothing they do will make any difference.

If their signals to tell us they are hungry, or have a sore tummy, or just need to be held (they signal by crying, or if you are nearby and available they might just grunt, nuzzle or whimper a little) are ignored, they will learn to distrust the outside world, their own bodies, and in particular to mistrust any influence they may have had on things *through their own actions*.

This is not very conducive to developing self-determination and self-regulation, and could even inflict lasting emotional damage.

*Don't worry if you can't breastfeed.* The contact, ritual, and closeness of feeding remain whether you bottle or breast-feed.

Plus, these days there are great bottles available which replicate the pressure and feel of breastfeeding, so that the baby doesn't guzzle and get a sore tummy, and are provided with the digestive aid and comfort that intensive sucking provides.



# Chapter 11

## Your own self-care

*No one can continue to support others if they work so much they reach burnout themselves.*

### Do...

- 1.** Try, if you possibly can, to arrange getting some time off. It is of vital importance that you get some regular slots of time (ideally even an entire day) when you are responsible for no other person but yourself.
- 2.** Be aware that the work you are doing is of fundamental importance to the world and to humanity, and among the most difficult, arduous and undervalued jobs that exist. Don't ever be tempted to minimise what you do. It is monumental. You are a superhero.
- 3.** Most of us are in urgent need of help and support (both moral and practical) which, in most of our situations, is sadly lacking. If there is any source of those in your area that is non-coercive, genuinely open-minded and helpful (whether friends, professionals or groups), try to tap into it.
- 4.** Online forums can also be really helpful and supportive. Some fellow-parents I know have, for example, a personal page where they share their family stories with their closer friends. At least in this way they receive empathy, and many loving, supportive thoughts and messages. This function can also be fulfilled through forums and online groups.



*Time off* is essential for your wellbeing (and therefore also for your family's). No one can keep on going – in any job – without any letup, night and day, seven days a week, year after year.

Stepping out of the thick of things, and getting some proper sleep, can give you a new perspective and some clarity on things that might be niggling you.

*Gentle, tolerant forums.* For me it's always been important to very carefully choose which forums and online groups I become a member of. I only join forums where I can see opinions are kept to an absolute minimum, and empathy to a maximum.

I found I had to limit the time I was spending online and on forums to a specific time of day when my kids weren't present. Otherwise I'd quickly get really frustrated and annoyed. I'm not, believe it or not, a natural multitasker. I go nuts.

5. If you are struggling, do try to enlist help. It may not feel like you can ever get out of the thick of things, but if you do not it's quite likely you'll burn out (I know this from experience). If not a family member, a partner, or close friends, perhaps a mentor or teacher figure your child likes spending time with – though I realise your finances would have to allow for this!
6. If you're suffering from emotional and mental exhaustion, your main priority is getting some rest, some time off, and some sleep. Try to get a massage or lie on a beach somewhere. If this is logistically impossible for you – then I am sorry, and my heart goes out to you...

# Chapter 12

## Other top tips

### Do...

- 1.** If at all possible, leave any formal diagnosis of autism until your child is old enough to understand and be actively involved in decision-making on this (if they are able).
- 2.** Be supportive and positive about your child's autism, if they do identify. Help them, if they are interested, find positive information and resources about neurodiversity. This will lead to them feeling confident about it and about who they are.
- 3.** If your child does *not* identify, it would be better to leave the subject alone, if that is at all possible. If they are unhappy about being diagnosed, I would advise doing everything you can to avoid that route – if this means you simply can't manage (what with any benefits or advantages a diagnosis might bring), then it will be necessary to gently talk to your child about the issue.
- 4.** Make it clear you will support your child in situations where they are being judged, put down, or sold short by others, even other grown-ups, even grown-ups in positions of authority.
- 5.** Get a set of noise-cancelling headphones in case of unavoidable noisy situations (on an aeroplane, for example).



6. Have a pair of sunglasses handy for your child to wear if they find it's too bright.

7. If you have doubts about specific situations and other aspects of parenting an autistic child, going onto autistic forums such as *WrongPlanet.net* can be really helpful. You can start a thread on your question, to see how autistic people respond (after all, who better to give some insight on what autistic children are likely to be experiencing?). You may well get some unexpected, resourceful and generally understanding responses and advice.



## Don't...

1. Don't use punishment to prohibit specific acts or behaviours (including withholding or confiscating nice things).
2. Don't use rewards (also known as 'positive reinforcements') including praise, in order to elicit certain behaviours. Using rewards diminishes any natural pleasure in a thing (like learning or being kind, for example), while it eats away at a person's trust in themselves (and therefore inclination) to do the right thing.
3. Don't persuade or force your child into doing things (where avoidable) where a specific wish has been expressed not to. Your child will challenge themselves and branch out when the drive comes from within, not from others (though opportunities and a

*'What am I supposed to do, then?'* If these first points leave you floundering, I would recommend two books: *How to Listen so Kids Will Talk, and Talk so Kids Will Listen* and *Siblings Without Rivalry* (see Reading List). They are full of excellent, practical advice, and have cartoon strips showing real-life scenarios in the home.

*'Opportunity not pressure'*. This was the strapline at the conference *Celebrating Autistic Culture*, arranged by and for autistic people (and described in *NeuroTribes*, see the Reading List), was, I think this is a very good approach for encouraging autonomy, confidence and self-determination.

conducive environment are essential). The long-term effect of external pressure is to inhibit self-motivation.

4. Try not to expose your child to people who overtly dislike or disapprove of them, and who don't appreciate their qualities.
5. Don't push gender roles. Let your child act and dress in a way that makes them feel relaxed. Only mention if they're going into a situation where they may be stared at or judged – I think it is only fair to give a warning to a child who might very well find themselves being looked at and laughed at without knowing why.
6. Don't judge or blame. Often we dress up blame nicely in words like 'facing up to the responsibility' – beware of this. There are reasons for everything. Assigning blame helps no-one.
7. Don't read books about parenting that advocate a 'technique' or regime (no matter how highly recommended they come!) Your instinct is a far more reliable guide.

*Parenting books.* There are many books that are not dogmatic or opinionated – instead tending towards being tolerant, kind, and realistic. And respectful towards both the child and the parent. I've included some of those I found most helpful in the Reading List.

Your child is a unique human being containing a soul and personality all their own. They are not an 'angel baby' or a 'difficult child' to be manipulated into conformity. And your relationship with your child is entirely unique too. Remember, whatever you read or are told, that *you and your child* are the world's biggest experts on this particular topic!

*A curious, questioning approach.* It is absolutely fine to question others' approaches and opinions (yes, even if they are experts and professionals!). In fact, it's essential if you believe that the welfare of your family is in the balance.

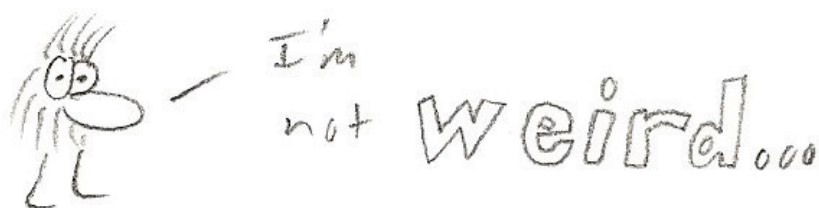
If people, rather than listening and being helpful, seem to you to be finding ways of shutting you down, it could be because they feel that some of their basic assumptions are being threatened... perhaps they feel their boat is rocking a bit too much (though they may also simply be stressed out, tired, or having a bad day, and just want to go home!)

**8.** Don't be blinded by authority. Psychologists, therapists, teachers and doctors have much valuable advice and support to give parents, but make sure you continue to think, analyse and research for yourself too (and remember, all of the above professional figures, if they're committed and creative individuals, will be open to exchanges of ideas and comparing of experiences).

**9.** Don't make rash promises to your child – they might have the memory of an elephant about those things, and then remember at the *most* inconvenient moments!

**10.** Don't worry too much if things go wrong, and you think afterwards that what you did or said was less-than-helpful – or totally disastrous, as the case may be!

**11.** And finally, it's essential to *never be hard on yourself*. Life should be as tolerable as possible for all those you care for, not least yourself. I saw a wonderful and charismatic presentation about compassion and self-forgiveness by a talented young man, Noah Britton, called *Autism: give me a chance and I will change everything* (available on YouTube). I'd highly recommend watching it, if you're feeling a bit hopeless about yourself and your difficulties. You will also see the beautiful side of autism.



- KLUNK -



# A note on trauma

If your child is showing signs of being traumatised by their current experiences, it's best you act immediately.

Typical signs and symptoms are listed below. If you see your child exhibiting a range of these together, you can begin to suspect persistent fear and anxiety—and resulting traumatic stress—as the root cause.

The greater the exposure to traumatic stress, the longer the period of healing will need to be, and the harder it will be for your child to recover. If you are in any doubt, it's far better to *remove them from potentially traumatising influences* while you try to understand the situation.

## Signs to look out for

Here are some of the signs and symptoms of traumatic stress commonly displayed by children.

- ✦ Outward character change (what has happened to my lovely, happy, kind son/daughter?)
- ✦ Persistent controlling behaviours.
- ✦ School refusal.
- ✦ Pervasive interest in death and suicide.
- ✦ Sudden, very strong, and often seemingly inexplicable reactions to triggers. Experiencing flashbacks.
- ✦ Sudden and frequent displays of strong anger and/or agitation (e.g. meltdowns – ask yourself what happened just beforehand, and what the possible triggers might have been).
- ✦ Chronic loss of appetite, or overeating.
- ✦ Major problems with focusing on projects, school work, and conversation.



- ✘ Persistently disturbed sleeping habits, and nightmares.
- ✘ Chronic memory problems (e.g. extreme forgetfulness and short term memory loss)
- ✘ Problems with speaking/verbal expression. (Broca's area—one of the speech centres in the brain—is affected.)
- ✘ Persistent regressive behaviours (e.g. bed wetting, 'tantrums', consistently needing a parent or teddy at night again, panicking about being left alone).
- ✘ Extreme acting out in social situations.
- ✘ Imitation of the abusive/traumatic event (look out for signs like cruel treatment of pets or younger members of the family, as this can be your child showing you what has happened to them).
- ✘ Persistent aggressive behaviours.
- ✘ Excessive screaming or crying.
- ✘ A tendency to startle easily, and to be very nervous or edgy a lot of the time.
- ✘ Inability to trust others or make friends
- ✘ Self-blame, self-hate, excessive shame
- ✘ Extreme fear of being separated from parent/caregiver.
- ✘ Fear of adults who might remind them of the trauma.
- ✘ Persistent anxiety, fear and avoidance.
- ✘ Chronic sadness and depression.
- ✘ Withdrawal and immobility (extreme listlessness, aimlessness, and marked tendency to 'freeze' when afraid).
- ✘ Extreme and persistent lack of self-confidence, feeling a failure and worthless.
- ✘ Persistent digestive problems, stomach aches and headaches.

*Children suffering from traumatic stress symptoms* generally have difficulty regulating their behaviours and emotions. They may be clingy and fearful of new situations, easily frightened, difficult to console, and/or aggressive and impulsive. They may also have difficulty sleeping, lose recently acquired developmental skills, and show regression in functioning and behaviour.

*This is the description of children who are suffering from trauma given by the NCTSN (National Child Traumatic Stress Network).*

*Current vs past experiences.* I talk mainly about current experiences here and not past ones (e.g. birth and hospital traumas in infancy). This is because of the possibility of immediate action and prevention.

For information on how to recover from past traumas, I would highly recommend Pete Walker's book *Complex PTSD: From Surviving to Thriving*. You do not have to be diagnosed with CPTSD in order to hugely benefit from reading the book.

*What's traumatic and what isn't?* Ah, a prize question! I'm afraid it isn't up to the parent or caregiver (or teacher, or other adults involved) to decide what a child *should* or *should not* find traumatic.

Every person's experience is unique, and whether or not the child suffers trauma as a result of certain experiences does not depend on our opinion about what they should be able to cope with at their age.

*Withdrawal and 'freezing' may go unnoticed.* Some quite severe symptoms of traumatic stress, such as withdrawal and immobility or 'freezing', can tend to go unnoticed in institutional settings (certainly when compared with things like meltdowns and aggressive outbursts).

## Avoiding and healing trauma...

### Why is this so important?

Your child's ability to cope with the more challenging situations in their lives will depend on them gaining a healthy self-esteem and resilience, and on being equipped with a tool-box of good coping strategies.

The results of continued trauma are real, and can be devastating. Developing the necessary self-esteem and coping mechanisms which will result in inner stability (strength, awareness, flexibility and endurance, even in the face of adversity) is not possible while the child is still in a chaotic state of panic due to ongoing traumatic stress.

As a rule, the more and the longer the child suffers, the more severe the symptoms will become, and the harder and longer the recovery period will be. You will need every last drop of your patience and endurance in order to deal with the fallout, and bring your family back to emotional health – this is why I can't emphasise enough how important it is to intervene and halt the kind of trauma that can damage your child's developing psyche, if it is within your power to do so.



# A bit of recognition!

Being a parent is such an enormous task that it's hard to know where to begin with this, but I felt I just had to add that I am very well aware of the difficulties in giving our children the kind of care and support we might wish them to have.

If your child is autistic – well, this seems to be the point at which we enter the realm of the unbelievable in how difficult it can become, but perhaps it's also the point at which many of us begin to question and change ourselves and 'how things are done', hopefully leading the way to real change for the better.

This is the reality: each of us is working mainly in isolation. Only the luckiest of families can manage on one income, or receive some kind of welfare support.

But even for those who have support financially, the fact is that we live in a world that does not value parenting or home-making as an occupation, either full or part time, and in which, when we do dedicate time to them, we are generally labouring away unseen and unrecognised in our little individual pods.

While those who also have to work for money, in addition to this, will find themselves not just on night duty to look after their kids, but most likely cleaning the bathroom at midnight, or sorting the toy cupboard before dawn (on no extra pay, and no recognition). How anyone can be patient and loving in such circumstances beats me!

I do not find this an ideal arrangement, as there is usually no adult company, no friendly sharing of work among equals, and no respite, particularly if you decide to home educate. No moment of freedom from responsibility and no real time off, not even at night.

Add to that the usual comments you get when you've answered someone who asks, 'What do you do?' If you say you're a full-time parent, they may answer, 'Um, what did you do before that?' and, 'So, when do you think you'll get back to work?'

The fault is not theirs, it's our culture which educates us to so devalue arguably the most important job there is – preparing our kids for their time in this world, and for what they may do with it.

Besides isolation and lack of recognition, another problem is that even if you do spend a lot of time with other adults, how many of those are your real 'clan'? Do you trust them, love them, can you spend time comfortably in silence with them?

Because of the way the world currently works we can't just automatically trust everyone around us. Many of us—more than one can imagine (since we're usually unaware of it)—have had our own experiences that can easily result in us behaving cruelly, neglectfully or inappropriately to others, including children.

The number of people with whom I would leave my baby is not high, even though I strongly believe it's best for babies and children to grow among people, to be held by others and not just their parents, to play and socialise with others of all ages, and later to be mentored by other adults and older kids – and here's another problem. Finding teenaged mentors who are relaxed in themselves, inspired and motivated, and loving what they do right now, isn't currently very easy.

So even if you do believe in the importance of community and sharing the load, it's a bit of a minefield.

It seems to me that what we are all suffering from, to varying degrees, is a deficit of real connection with others and of community, as well as lack of free time and time spent quietly and in nature.

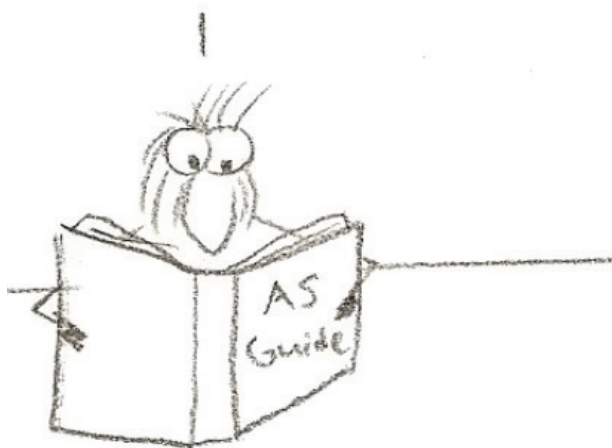
All I can say is that in such circumstances it is very difficult to raise our children with all the joy and humanity we would wish them to experience now and in their future lives.

So, if you manage to achieve it even just a little—and with however-many lapses and confusions along the way—then you are not only contributing to your child’s happiness and future, but to *everyone*. You are actively contributing to the creation of a more humane and beautiful world for us all.

**Here’s to you, parent and miracle-worker!**



Me...  
me...  
oh, that is so me!  
I rock!



# Reading List

These are the books, articles etc. that I have found most interesting and influential in my research. I realise they are quite diverse!

**The Complete Guide to Asperger's Syndrome**, Dr. Anthony Attwood. *Jessica Kingsley Publishing 2008.*

**Radical Compassion: Learning to Love Yourself and Your World with the Practice of RAIN**, Tara Brach. *Rider 2020.*

**BBC iWonder: How does a child experience autism?**, article presented by Carrie and David Grant <http://www.bbc.co.uk/guides/zgdhwxs>

**The Ascent of Humanity: Civilization and the Human Sense of Self**, Charles Eisenstein. *Evolver Editions 2013.*

**How To Talk So Kids Will Listen and Listen So Kids Will Talk**, Adele Faber and Elaine Mazlish. *Piccadilly Press 2012*

**Siblings Without Rivalry: How to Help Your Children Live Together So You Can Live Too**, Adele Faber and Elaine Mazlish. *Piccadilly Press Ltd 1999*

**Changing Our Minds: How children can take control of their own learning**, Dr. Naomi Fisher. *Robinson 2021*

**Madness and Civilization: A History of Insanity in the Age of Reason**, Michel Foucault. *Vintage Books 1988*

**The Art of Loving (Classics of Personal Development)**, Erich Fromm. *Thorsons 1995*

**Emergence: Labeled Autistic**, Temple Grandin. *Grand Central Publishing 2005*

**Why Love Matters: How Affection Shapes a Baby's Brain**, Sue Gerhardt. *Routledge 2014*

**Smart Moves: Why Learning Is Not All In Your Head**, Carla Hannaford. *Great Ocean Publishers 2005*



**Healing Developmental Trauma: How Early Trauma Affects Self-Regulation, Self-Image, and the Capacity for Relationship,** Laurence Heller and and Aline LaPierre. *North Atlantic Books* 2012

**The Reason I Jump: One Boy's Voice from the Silence of Autism,** Naoki Higashida. *Sceptre* 2014

**How Children Learn,** John Holt. *Da Capo* 2017

**Teach Your Own: The John Holt Book Of Homeschooling,** John Holt. *Da Capo Press,* 2013

**Never One of Them: Growing Up With Autism,** Lance Earl King. *BookBaby* 2016

**No Contest: The Case Against Competition,** Alfie Kohn. *Houghton Mifflin* 1992

**Punished by Rewards: The Trouble with Gold Stars, Incentive Plans, A's, Praise and Other Bribes,** Alfie Kohn. *HarperOne* 2018

**Waking the Tiger: Healing Trauma,** Peter A. Levine. *North Atlantic Books* 1997

**The Continuum Concept,** Jean Liedloff. *Penguin* 1989

**Last Child in the Woods: Saving Our Children from Nature-deficit Disorder,** Richard Louv. *Atlantic Books* 2010

**The Intense World Syndrome – an Alternative Hypothesis for Autism,** Markram et al., 2007. Abstract available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518049/>

**Children with Emerald Eyes: Histories of Extraordinary Boys and Girls,** Mira Rothenberg. *North Atlantic Books* 2003

**An Anthropologist on Mars,** Oliver Sacks. *Picador* 2012

**Reasonable People: A Memoir of Autism and Adoption,** Ralph James Savarese. *Other Press LLC* 2007

**NeuroTribes: The Legacy of Autism and How to Think Smarter About People Who Think Differently,** Steve Silberman. *Allen and Unwin* 2016

**The Rosie Project: A Novel**, Graeme Simsion. *CreateSpace Independent Publishing Platform* 2015

**Far From The Tree: Parents, Children and the Search for Identity**, Andrew Solomon. *Vintage* 2014

**The Body Keeps the Score: Mind, Brain and Body in the Transformation of Trauma**, Besel Van Der Kolk. *Penguin* 2005

**Nobody Nowhere: The Remarkable Autobiography of an Autistic Girl**, Donna Williams. *Jessica Kingsley Publishers Ltd* 1998

**The Autism Spectrum: A Guide for Parents and Professionals**, Ms Lorna Wing. *Robinson* 2003

**Complex PTSD: From Surviving to Thriving**, Pete Walker. *CreateSpace Independent Publishing Platform* 2013

**The Child, The Family And The Outside World (Classics in Child Development)**, D. W. Winnicot. *Penguin Classics* 2021

**Care in Normal Birth: a Practical Guide**, World Health Organisation.

And there are so many fascinating and relevant books and articles out there that I have not read yet! I'm still very much on the case, and I love to have recommendations about what to read next.



## Grandmother's Wisdom

My mother has two most-used responses to many of the worries or doubts I or my sister have had about our children, or about parenting in general. I find them possibly among the nicest and most helpful comments a grandparent could make.

Here they are:

*'Parenting is not really so much about what you should do, it's more about what you can endure.'*

*'He/she probably won't be doing it when he/she's fourteen.'*



## About the Author



**Katy Elphinstone**, besides being a full-time mum, works part time in admin at a Camphill Community for adults with learning disabilities in Scotland. She is active as a speaker and writer, and as a mentor offering encouragement, materials and advice to other parents.

## About the Illustrator



**Matt Friedman** is a grant writer, fundraising professional, and cartoonist. He is the author and artist of *Dude, I'm An Aspie*, which depicts life with Asperger's Syndrome with honesty and humour, using simple yet effective cartoons that are more powerful than words.

Copyright © 2017 by Katy Elphinstone

Images used in this book are copyright © Matt Friedman, reprinted with permission.

*Dos and Don'ts, Autism and Asperger's Advice for Parents and Carers* is a practical, lighthearted and accessible book. The suggestions given are readable and overall quite do-able, giving the reader the pleasure of a smile or two along the way.

The book is arranged into topics, *At home, Out and About, Friendship, Communication, Health and Hygiene, Bedtime and Sleep, Physical Contact and Emotions*, and more. A wide range of day-to-day situations and probable challenges are covered. Suggestions are given from a deeply gentle and understanding perspective, both of the children themselves and of the difficulties and doubts we all experience as parents.

The overall approach aims toward achieving better connection, growth and understanding on all sides – child, parent and society at large!

*Dos and Don'ts* is illustrated by the well-known cartoonist Matt Friedman (also the author of *Dude, I'm an Aspie*).

*"What do we have in common as parents and carers of autistic children? Well, probably concern and worry for a start, about how they might do or might get along 'out there'!*

*Certainly the feeling of loving your child so much you'd probably go to the world's end and back, if it would help them to be okay...*

*And a deep wish to support them in finding their own way in life, in achieving inner equilibrium and resilience, and in becoming self-confident – and the strong desire that through these things the chance will be gained for their gifts to shine through and be appreciated fully, both by themselves and others."*

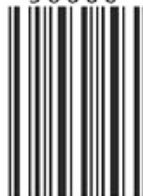
**“I love Katy’s energy and kind approach. It’s an easy read... I’d have loved to have found it 15 years ago when my son was 5!”**

**Samantha Craft, *Everyday Aspergers***

ISBN 9781999733506



90000



9 781999 733506