

# The A-Z of AS by Dr. Zehanne Kenny





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# Introduction

Dr. Zehanne Kenny was a student of Trinity College Dublin completing a PhD in English & Philosophy researching consciousness as a theme within the Shakespeare play Hamlet. Zehanne sadly died on Saturday 23rd October 2010 and is deeply missed by all who knew her. To say that Zehanne left an impression on everyone she came in to contact with would be an understatement. She would do the rounds of the Arts Building speaking to all of her 'usual suspects', of which I was one. It was usually at the end of a long day and her humour was an antidote to any battle that had taken place earlier in the day. Zehanne was a blind woman with Asperger's Syndrome and would be best described as eccentric and highly intelligent, and challenged us all for the better. She campaigned tirelessly to make the College and the wider world more accessible.

This booklet is written with the aim of helping students diagnosed with Asperger's Syndrome to deal with some of the difficulties that face them as they enter college life for the first time. Coming into a strange and unfamiliar environment, with all the pressures of academic and social life, many students feel overwhelmed and frustrated in such a new world. Zehanne writing from her own experience as a student with AS has provided several stories and tips to help students deal with the problems they face as they integrate into college life.

Dr. Zehanne Kenny unfortunately passed away before the publication of this booklet, so cannot see the fruits of her work and how much we appreciate her enthusiasm in helping us with this project. It is as much a memorial to her memory as it is an AZ handbook and we have tried to be respectful to her memory in our efforts to edit the book, leaving a style that is at times idiosyncratic, yet utterly amusing and intriguing. We hope you find that her work helps you as you take your first steps into college.

## Declan Treanor, Director College Disability Service, Trinity College Dublin September 2011

# Zehanne Kenny a few thoughts – about a unique woman:

#### A woman of determination:

I actually met Zehanne when she popped into the Librarian's Office to lodge a complaint about the absence of the Library Disability Officer. I listened intently and responded politely, but it wasn't good enough for Zehanne, who went off to her supervisor, to lodge a formal complaint. She was a woman of determination.

### A woman of humour:

We hit it off from the start, I think because we enjoyed each other's humour. She would inevitably see the funny side of things and have me laughing. She had a hardy laugh and a lovely smile.

#### A woman with a positive outlook:

She would often pop in to have a chat and let me know how she was. No matter what was happening in her life, she always seemed to inject it with a funny story or some positive information. When she was going through the issue with her swollen hands – she would put on a brave face and look to when she would be back to normal.

#### A woman who was focussed:

When Zehanne got an idea in her head she relentlessly pursued a solution. She wanted a quieter workstation and would often be in my office reminding me she needed to relocate, why she needed to relocate, and wanting to know when she could relocate. It is sad to think that I had actually found her the perfect location – which she never saw or took up residence in.

#### A woman who was thoughtful:

Right from the start – I made Zehanne's acquaintance after I started in College in July 2005 – she never forgot to send me a Christmas and Easter card – handmade and colourful. She understood if you couldn't stop to chat and would return when you had time to give attention to her needs and issues. Her work on making us understand autistic adults was relentless.

#### A woman worth knowing:

Although my contact with Zehanne was limited, sporadic and brief, I still feel it was a privilege to have known her. Our paths no longer cross, I don't get her little cards anymore, and I miss her banter and jokes. She touched my life.

#### Jessie Kurtz, Deputy Librarian, Trinity College Dublin



# **Disclosure – Read this bit first**

Always remember that the fact of being autistic is private, yours to disclose or not. However, there are definitely some circumstances where disclosure is the best option. Dawn Prince Hughes, speaking on the subject of those who might advise against, writes:

"I have been told that the people in question (i.e. those who advise against disclosure) want to save the autistic person from the 'stigma' of being autistic. I don't think they realise how stigmatised people with autism are – because of their behaviour, not because of any label."<sup>1</sup>

I generally disclose – some people, especially in a college situation, may know already; few will know how it impacts on your everyday functioning. Another point to bear in mind is that once a bad impression has been created, it is very difficult to erase. Most people will be interested and eager to learn more about a condition they may only have seen in text books or in extreme forms. This places you in the position of teacher, a position you should occupy with as much honesty and sincerity as you can. You will be adding to the knowledge base society possesses about people like yourself. A worthy project indeed.

You will be amazed how many times you get asked the exact same question by different people. As Lawson (2002) wonders:

"Why do so many neurotypical individuals have such problems understanding ASD? I would like to suggest it is because ASD cognitive processes are so different, and just using one's intellect to gain understanding of those differences isn't enough. It is also important to appreciate ... what they mean for the individual and their families, and how these differences can be useful in positive practical ways."<sup>2</sup>

<sup>1</sup> Prince Hughes, D., Songs of the Gorilla Nation: My journey Through Autism, Souvenir Press: London, 2004 pp. 174 5. 2 Lawson, W. Understanding and Working within the Spectrum of Autism, Jessica Kingsley: London 2002 p.2

<sup>2</sup> Lawson, W. Understanding and Working with the Spectrum of Autism, Jessica Kinglsey; London 2002 p.2

Luckily, for me, I was able to reinforce my initial "I have high functioning autism" with an invitation to look up articles on the college website for further information. It also helps if you can recommend any books you may personally have found helpful. Above all else avoid delivering this information in a style that is either arrogant or apologetic. A sincere tone is best (practice on it if you have difficultly sounding sincere!) And be prepared for any questions.

Unfortunately, once you've explained and once the person you are explaining to says "Oh, I see..." DON'T assume they do! I've had many encounters with people who verbally make all the right noises of agreement, so I figured they:

- a) Understood
- b) Accepted

However, as soon as something occurred which made me behave in an autistic manner then they would react with shock and horror, with "what kind of a monster are you...?" etc. I got used to it, so if it happens now, at least I've taken out my insurance policy, so I'm covered for autistic behaviour. If the audience says they get it when they don't then I did my bit; they have the problem.

## Summary

Disclosing might be better than being misunderstood.

If you disclose, you'll get questioned, over and over....

Try researching books and websites to recommend.

When someone says they understand – don't assume they really do.



# Acting

This one is a real problem, and can often turn into a no-win situation however carefully you handle it.

Most people on the spectrum find that playacting and behaving as though they were really neurotypicals is a good way of being accepted. Well, it is – but be warned – it has a down side. Paradoxically the better you are at it and the more successful, the greater a toll it will take on your energy levels.

Acting involves speaking, gesturing, having facial expressions and body language – and, if none of this comes naturally to you, then you have to constantly and consciously monitor yourself to keep it going.

Neurotypicals behave the way they do because it is how they are – people on the spectrum can observe and copy these behaviours, but cannot genuinely be like that. Behaviour that is deliberately manufactured – as opposed to behaviour that is spontaneous – exhausts us!

You may well find that, at first, when you seem to be getting on well and doing a good job, you experience a buzz and the whole thing doesn't seem so bad.

Beware! Buzzes don't last very long, and being obliged to keep on producing behaviour which works, socially, but which drains internally is hardly a way to go.

My advice would be – compromise. Ok, so you want to be able to negotiate the neurotypical world as efficiently as possible, but don't put outrageous demands on yourself. Aim for behaving in a way which is passably socially acceptable – but which you can maintain without undue strain.

There are few things as disheartening as getting to know people, relaxing into a more "normal" mode of behaviour, and being asked, "Are you ok? You're usually so cheerful – is something wrong?" A lot of people on the spectrum find themselves totally worn out at the end of the day – which is bad news physically, mentally and emotionally.



## Summary

Acting as something you're not can be very exhausting.

Being accepted as a fake means having to keep faking.

It makes more sense to behave in a way which gets you by, but which doesn't place unreasonable demands on your physical and mental health.



# Alcohol

This substance needs careful handling since, as most people on the spectrum discover the hard way, your metabolism may not process alcohol in the same way as a neurotypical one does.

You need to experiment to find out which types of alcoholic beverage suit you and which definitely do not (unless of course you decide not to touch the stuff at all which is probably the safest way to go).

Experiments are best not carried out in bars. Experiments are best carried out alone or with friends and family. Don't base your own behaviour regarding alcohol on observation of how it affects neurotypicals: some neurotypicals can drink a lot, mix different drinks, and wake up next morning without a hangover; while other neurotypicals can only drink a very small amount before becoming either violent or ridiculous, and then wake up next morning in utter agony.

Try a few beers (German and Austrian are generally less chemically enhanced) or some wine to see what the effects are. Vodka is probably the least chemically adulterated of spirits, though it is incredibly strong (with an average alcoholic

content of 38% by volume, compared with the 7.5% in Guinness). Remember that until you drink, you can't know what is going to affect you and what isn't. You may not, at the time, realize you are being affected, hence the value of friends and family who will soon notice a difference in your behaviour (unless they unhelpfully allow themselves to get drunk alongside you.)

Bars and parties can be attempted if you have a good idea of what you can drink and how much. Unfortunately it is very, very easy for things to get out of control so staying with a friend or two you can trust is the safest option.

If you find – as I did – that alcohol makes you feel ill and definitely does not produce any kind of a buzz then fair enough – you tried, but metabolically you and alcohol are not going to be friends. If, on the other hand, you do get on quite well with it, then you need to be very careful how and when you indulge. Do not get the idea that, if it does give you a buzz then taking it home and drinking it copiously and covertly is a great way to improve your life.

## Summary

Experiment in safe situations first.

Get to know what suits you and stick to it.

Remember your metabolism may not be the same as a neurotypical one.

If alcohol gives you a nice buzz, do not abuse it by becoming a stay at home alcoholic.



# Belief Versus Fact /Opinion Versus Truth

What does being honest mean? One thing it could mean is telling the truth. Unfortunately, unless you are a Zen master, a certified genius, or an omniscient deity, you are unlikely to know the truth. In fact, when you speak what you assume to be the truth, all you are really doing is giving an opinion.

Small children often blurt out things they think are true, but, and it's a considerable "but", a lot of the stuff they blurt out will be positive.

Oddly enough the stuff blurted out by so called truthtelling adults is rarely, if ever, positive. Indeed, most of the time it is hypercritical of everyone and everything. It seems a lot easier to be spontaneous with all your negative opinions and very difficult with anything positive.

Genuinely honest people don't go around labelling themselves as "honest". People on Autistic spectrum often do. "My honesty is one of my best qualities" is a familiar phrase. Genuine honesty is a way of being in the world which will be recognised and labelled by others who benefit from it, like genuine courage and generosity. "I am brave" or "I am generous" are only amateur efforts to get people to make those judgements about you – without any supporting evidence these statements amount to nothing. "I am honest" is merely a mandate to inflict your opinions on others and, make no mistake, these others will see it exactly for what it is!

You might, reading this, quite reasonably ask: "Why – if people don't like what I say, don't they show it? I always show what I feel.

This might be true, but it is also true that most people have a totally different way of dealing with something which they hear and don't like. Here's how it usually goes. Say you make a remark about how you don't think a particular hairstyle suits them, or how they are too big for the dress they're wearing. At the time you make your remark the person doesn't seem too upset, though they often are. We autistics also aren't very good at reading the feelings of other people so even if they are acting upset, we may not see it that way, or understand why they would be given the circumstances. In order to feel less upset neurotypicals go to someone else and report what happened. The two of them then combine in suggesting reasons why your original remark was invalid. The reasons will all be of the form that you were wrong and rude and, if your Autistic Spectrum Disorder is known, that will get the blame. A normal person would not have said what you said, only someone abnormal – in a very negative subnormal way.

Result? You get passed around from mouth to mouth, and acquire a bad reputation, while the person you insulted albeit unknowingly, feels ok again. Obviously this is not the way to go, although "I am honest" may have seemed a great label to stick onto yourself. The problem is that with all social interactions, learning a principle, however admirable, then applying it ruthlessly like a mathematical formula does not work. Honesty expressed as an opinion is liable to do more harm than good. Doing good to other people is not easy, it's very hard and not many get it right – autistic or otherwise.

Part of doing and being good is knowing what will help others, on a one to one level. It requires a willingness to observe, to ask if necessary, and to come up with creative solutions to individual problems. There is no formula you can learn and apply consistently. Short of abandoning honesty, what can you do? Something worth trying is making positive comments or none at all. An opinion is not a fact. You do not have a monopoly on truthtelling. Be honest about that.

## **Summary**

Don't mistake beliefs for facts.

Don't mistake opinion for truth.

You rarely get away with insulting people.

If you can't say something positive – a closed mouth is probably the best idea.



# **Birthdays**

Neurotypicals usually love these (well, neurotypicals generally like celebrations so I suppose a date on a calendar is as good a reason as any other). I, personally, couldn't care less for such things and prefer to carry on as usual and follow my routines each and every day.

Maybe you enjoy celebrating birthdays, which is fair enough, but the point I'm making is about neurotypicals, not about you. As I said they really love birthdays – even the neurotypicals who don't seem to care, never tell you when their birthday is and who just shrug it off when you do find out and ask them what they'd like.

Once you know a birthday date – keep a record. Write it down on the calendar, in your diary, or log it into your phone or laptop or whatever, then don't mention again till it's relevant.

When the date comes around make sure you provide a nice card, or maybe a gift – even if you're not best friends with the person. Some little token will be greatly appreciated – gift vouchers, cinema ticket, buy them a drink, perhaps a Tshirt with their favourite band on it, etc.

Now for something you should never, ever, do (especially when it's a female's birthday): never ask how old they are. Taboo with turbos! This is the equivalent

awful question of asking somebody how much they earn. Not only will offence be almost certainly caused, but, if the question is overheard, it'll mark you out as a socially inept weirdo.

Ultimately – ask yourself if it matters how old someone is? You can easily categorize most people into "young" and "old" you don't need a number. If you really need to know try asking a close friend or a family member instead of the birthday boy or girl to avoid causing offence. Usually this isn't a problem for young people in college, as most of them revel in their increasing age, and it's only after age 30 that it becomes a concern for them.

A word about cards – be careful, a lot of humorous cards are actually deeply insulting. Avoid things which poke fun at the person you're giving it to – particularly if that person could be categorized as "old"

Here are a few definite NO NO'S:

Cards which make fun of baldness. Cards which depict older people chasing after younger ones. Cards which seem to assume the receiver drinks a lot. Cards which assume the receiver is really stupid. Cards portraying the receiver as sexually promiscuous. Cards targeting people who dress in clothing considered age inappropriate.

In fact humorous cards can be a real minefieldyou're on much safer ground choosing a nice landscape, a sporting scene or if you don't mind paying a bit more – something with a famous person like Marilyn Munroe or Bruce Lee. If you can draw a bit, then you might make your own card – but if you do, keep the list above in mind!

## Summary

Neurotypicals – even when they pretend otherwise, seem to really like birthdays.

Keep a record of birthdays somewhere safe. A card or a gift will be greatly liked BUT – Be very careful about asking anyone their age.

Don't buy a card which is funny but potentially insulting. If you can, make your own personalized cards.



# Cinema

Nothing beats going into that vast, dark, enclosed entertainment space, and watching a huge screen full of thrilling images.

Yeah right. What about the guy rustling his bag of toffees on your left, the couple whispering and giggling on your right and the jackass behind who can't keep his feet off the back of your seat?

Even before any of these pests get going, what about waiting outside for someone to turn up? Chances are, you will be on time or even early, while they'll be late. So, do you wait or go in? If you wait you will have to stumble around in semi darkness trying to find a decent seat, but if you go in the late comer might not be able to find you, so you will be watching the movie on your own anyway.

## Solutions?

Going alone is one – going early in the afternoon is another, but to be honest, however you fiddle about, cinema can equal stress for you.

I've gone to movies and by the time whoever turned up, found I was so stressed out it was hardly worth going in! Alternatively I've gone alone and been tormented by the rustlers and the talkers.

One more thing – if noise bothers you – as in loud noise – bring something for both ears.

Of course none of the above may get you down (lucky old you), but if they do, and you still want to go to the cinema, then try to go fairly regularly, about once a week. If you stop going then it's very, very hard to get back the routine you've built. This can be applied to most stressful situations.

## Summary

Unless you don't mind the stress of hanging about, go alone or with very reliable time keepers.

Bring something for your ears if noise is a problem.

Matinees are generally less packed with noisy audiences.

If you find cinema stressful – but want to keep going – try to establish a regular day – getting back to the routine once you have given up for a while can be mega tough.

# **Concerts/Festivals**

You might have problems with these, particularly if you have not been to one before.

The first thing to do (well, actually the second, the first thing to do will be to get your ticket) is to figure out the logistics of getting there and getting back. If the concert is your first, then rather than going to a festival, try choosing something that takes place in a local club or stadium.

How exactly will you get there? A lot of neurotypicals leave this to the last minute – you will probably feel more comfortable if you have the details planned and confirmed. Are you going alone or with family or friends? Generally going alone is not the best idea unless you've been to concerts before and have a clear picture of what to expect.

What about facilities? Eating, toilets and sleeping (if it is a festival) have to be considered. Neurotypicals of your acquaintance may make it all sound like effortless fun – which may not be true for you, particularly if you're a careful planner and like to know what will happen and in what sequence. When you get to the concert venue you may not be able to handle the crowds, or the noise or the lack of structure, or any of these three.

Neurotypical concert goers often indulge in alcohol and various illegal substances. If this does not appeal to you, then be very, very, careful who you go with. If the people you're with don't know much about the spectrum (or even the fact that you're on it) then their attitude towards you might be something along the lines of: "He/she just needs to loosen up a little, then he/she will be fine".

Bottom line – don't assume that just because several neurotypical friends went to such and such a gig and had a fantastic time, the same will be true for you. Different needs/different strengths and weaknesses etc. will equal different experiences for everyone.

Leaving aside the concert itself, don't forget that once it's all over, you have to extricate yourself from the venue in an intact state. Even neurotypicals find this extremely awkward. Large crowds all moving in the same direction at the same time can be very intimidating.

Ultimately you may find that your favourite bands sound a lot better in the recording studio with perfectly mixed tracks, state of the art acoustics et al. The main buzz from a live performance might not mean all that much to you.

Experiment a bit if you can – most bars and clubs have a live music night. See how comfortable you are with that kind of thing before splashing out money on a big night.



## Summary

Concerts and festivals need to be planned for. What suits neurotypicals may not suit you.

Make sure that the people that you are with don't have a false impression of you.

Be prepared for large, large crowds.

# **Cross cultural Interactions**



I've often thought that an autistic individual can never really have a first language since even their own native tongue is a product produced for and by neurotypicals to express a neurotypical reality. It follows (if I'm right) that dealing with people who may be neurotypicals, but whose interactions have to take place in a second language brings about a kind of common ground situation. Those who learn English as a second language have to learn and master not only the English syntax and vocabulary and all that stuff, but a whole new bunch of idioms and verbal idiosyncrasies. Not only that but they usually have to figure out all the unwritten rules of socially manoeuvring through a foreign cultural milieu. Exactly like autistic people!

Besides all of this (plus the novelty value of being exposed to other cultures) there is the fact that a lot of ethnic groups come from societies with more structure and a lot more respect for God, for family, the police etc. This shows in their behaviour and especially in their conversation. In some cases, they might have a greater toleration of, and interest in, people and a greater willingness to learn, share and above all help. Different codes of everyday behaviour manifest themselves in such ways as showing their feelings in a much more open and easier to understand way, and by having a much greater latitude of tolerance before their censorious mechanisms kick in (unlike most folk here in the west where individualism rules and the dollar is deified).

However, it is important to remember that, when dealing with people from another culture, you should be careful about making inaccurate or biased assumptions about them on the basis of their cultural or ethnic background. For example, don't assume that someone from the United States is an imperialistic, guntoting slob on the basis of a media stereotype, but do listen to them and get to know them as a nuanced individual. Treat people with politeness and respect regardless of their race or nationality, and avoid making generalizations about people based on their culture.

## Summary

If you like the metaphor that being on the spectrum equals being part of a minority culture then use it to explore the implications.

Not only are many "foreigners" in the same minority position as you, but many have a refreshingly alternative outlook to the competitive, individualistic western ideal.

Avoid making assumptions about people based upon cultural stereotypes.



# **Excuses v Reasons**

Usually a "reason" is something you believe – an "excuse" is something you want others to believe.

Neurotypicals use excuses all the time. A neurotypical might say "I can't play chess with you tonight – I really need to study." My advice is to accept it. Don't offer to help him or her study and don't suggest an alternative night for the chess. Neurotypicals use excuses all the time to avoid saying "Sorry, I don't want to play chess with you." They find this so hard to say that they prefer elaborate excuses.

If, by the way, the excuse is genuinely a reason, then the person who made it will soon get back to you suggesting another time for the chess.

So how about the case where you don't want to do something; do you say so bluntly or do you use an excuse?

Compromise is often the best thing to do. Instead of saying "I don't want to," try something along the lines of "I really don't feel like it tonight" (or "this week" or "lately" or whatever).

Don't invent stories about having to be somewhere else – you need a pretty good memory for this kind of thing and it is very easy to be caught out.

## Summary

Reason = something you believe. Excuse = something you want others to believe.

Neurotypicals use excuses rather than truthfully telling you they don't want to do whatever it is.

When you don't want to do something – use a partial reason, making it sound like you don't – at this time – want to do it.

# **Food - Hunger and Nutrition**

As Dawn Prince Hughes says:

"Inever experienced physical sensations of hunger and thirst, and as a result I am often dehydrated, which leads to headaches and dizziness"<sup>3</sup>

Thirst, hunger, pain, being too hot or too cold, even tiredness are all sensations which many people on the spectrum can ignore- if they even experience them. Even when you do register things like hunger and thirst, you may well be a "faddy feeder". Some food types you eat a lot of, others not at all, and, unless your preferences are nutritionally viable, you could end up with all kinds of deficiencies.

It is comparatively easy to make cause and effect connections between many things, most of them being mechanical in nature (e.g. switch ON =light I OFF= dark). Biological matters are more complicated and generally take longer to manifest their cause and effect scenario. There are obvious exceptions: Finger into hot water= pain, (although, this may not be exactly the same as the neurotypical finger/hot water/pain experience.) Anyhow you, and definitely I, might have a problem establishing the link between eating right and being healthy.Why, you might wonder, if your body needs food the same as a neurotypical, do you not have a useful little "hungry" signal? Not fair at all is it? However you can get around the problem by doing some research into the kinds of stuff you should be eating and how much, then make it part of your routine to do it properly.The laptop whizzes can do proper diet sheets for themselves.

It's a good idea to try out unfamiliar foods. You might be surprised to discover that something you ate once, possibly as a child and previously disliked, is now quite palatable and healthy to eat.

<sup>3</sup> Prince Hughes D.p21

## Summary

Some people on the spectrum have little or no awareness of hunger or thirst.

Many others are highly eccentric eaters.

Some modification of what you consider "normal" eating behaviour may be a good idea in the long term.



# **Food – Dining Out**



Unless you like to cook, it's a good idea to find a nice, friendly, cosy, quiet, healthy menu'd, cheap place to eat. In fact, having found one – find another, then alternate your visits. Having only one means you're vulnerable to the place closing down or getting new management and changing its character.

Trying out different places can be an ordeal (it was for me) so here are a few things to bear in mind:

- 1. Staff: Friendly or abrupt? This is crucially important if you have unusual dining needs.
- Time of the day, If you don't want to dine among noisy crowds then you need to pick and stick to certain times of the day.
- 3. Music: Is there any background music? If so is it turned to an acceptable (for you) volume? If not, is it ok to request it goes down?
- 4. When reading using laptops etc. be careful! Some places don't seem to mind – especially when they're not full. However, don't assume you've found a private study area. A good place to eat should be primarily just that – don't abuse it!
- 5. Talking to staff: Even if they are friendly and even if you find someone who has similar interests to yours, DON'T chat on and on while they're supposed to be working. Even the most open minded manager will soon notice and object. He or she is not paying wages for chatting to customers.
- Food: Try for a place with healthy options it is very easy to repetitively eat stuff that's tasty and stuff that's familiar but it's always a good idea to try new things.

## **Summary**

If you do find a userfriendly place DON'T abuse it by turning it into a study area.

Be friendly with staff but be careful of having lengthy conversations when they're on duty.

Once you feel reasonably at home, start trying a few unfamiliar foods.

Try hard to find somewhere with both healthy options and reasonable prices.



# Friendship vs. Professional Relationships

Sometimes a person's behaviour to you can lead you to believe you have a real friendship but in actuality it isn't.

Generally this happens to people on the spectrum when they mistake the attitude of a professional for genuine friendship. The professional – lecturer, social worker, counsellor or whatever is – so far as they themselves are concerned, behaving in a friendly and appropriate way. Unfortunately the person on the spectrum misinterprets this, thinks they've found a friend and acts accordingly. Then, one day, they do or say something which violates a set of "professional" boundaries that they never knew existed. The result? They get told they've gone too far. This can leave you feeling like you never want to talk to anyone ever again, usually a temporary state, but nasty while it lasts.

One thing you can do is observe the professional when dealing with other students; for example, do they treat these others the same way they treat you? If so then you can be pretty sure it's a general mode of behaviour and nothing special for you and you alone.

You can and should treat all professionals in a friendly way, but do so as if you were the lecturer and they were the student. I.e. be as good humoured, pleasant, helpful and nondemanding as you can.

Of course it is possible to become friends, real friends, with a professional but usually not while you're in a teacher/student, counsellor/client or similar relationship.

There are a lot of deterrents for professionals getting involved to any depth with students or clients. They could even face criminal prosecution. Most of them wouldn't take the risk – the few who do are not worth your taking the risk for.

## **Summary**

You can really get hurt if you mistake a professional manner for real friendship.

Observe how they treat others in your position; they probably treat them in a similar way.

Getting into a relationship that goes beyond professional boundaries is not a good idea – a professional who does this is behaving irresponsibly.

# Hands – Shaking and Washing



The handshake: for reasons I admit I cannot work out, is a hangeron from the good old days when people used to carry things like swords. The extending of a swordless hand supposedly conveyed nonviolent intentions. This explanation is the only one I have managed to unearth for such an unhealthy custom. I have not managed to unearth any logical reason for its continuance. Assuming you do find yourself in a hand shaking situation, try not to touch your own nose, mouth or eyes until you've washed the (possibly) contaminated hand.

WARNING! Clean is good; obsessive hand washing is not! Many people with AS are inclined to overdo things. Obsessive hand washing, please remember, is counter productive: skin contains glands which secrete your own personal antibodies. These help keep bacteria at bay, a protection which gets lost if you keep scrubbing.

## Summary

Neurotypicals shake hands because of some antiquated custom.

It's a great way to transfer germs.

After a shake you can't avoid, wash your hands before touching anything important, especially your own face.

Don't go overboard with hand washing – when it becomes obsessive is when it becomes counterproductive.

# How are you?



I detest questions like this. I never know what to do with them and care less. A professor once asked me the question when I was in a bad mood and got viciously snapped at.<sup>4</sup>

I think the whole "How are you?" scenario is about as much use and as logical as the hand shaking scenario (described earlier on) ,but I recently came across an interesting little piece by Peter Nadas (Hungarian). He claims that when two people living under an oppressive regime meet, "How are you?" is answered by cataloguing all the awful things that they have to suffer in everyday life. On the other hand, when two people in a democratic Society meet, the question "How are you?" is answered by "Fine thanks."<sup>5</sup>

Why so? Well his opinion is that the oppressed people's solidarity with each other is best expressed by swapping

<sup>4</sup> Luckily he was big enough to understand and apologise

<sup>5</sup> See Nadas P., Fire and Language: fiction and Essays, Picador, New York 2008.

bad luck stories. i.e. they themselves are victims rather than being in control of their fate. In contrast those in the democratic society are (or so they hope), in control of their fate, so coming out with a lot of negative stuff would be the same as admitting they messed up big time.

One simple way to deal with: "how are you?" is to proudly exhibit your latest skin abrasion. If you're anything like me, you'll find a few new ones every day and this includes bruises, cuts, splinters, scalds and thorns or cactus spines. The mystery is: how were they acquired? I have never had much of an idea (Unless it's glaringly obvious e.g. "I'm purple and red with nettle – rash because I fell into nettles.")

Probably the difference in autistic / neurotypical pain and other sensations accounts for my battleground body. If your body is otherwise free of noticeable blemishes or marks, perhaps you could mention how your day has gone so far, or a particularly interesting story that you've recently experienced. Anyhow you might be able to modify this idea and use it with good luck.<sup>\*6</sup>

## Summary

How are you?" is too broad of a question.

There seems to be a difference in democratic and non democratic states in its use.

If you have mysterious skin abrasions try talking about them and see if it gets you results.

<sup>6</sup> To be 100% honest I generally never notice my battle scars until someone else points them out to me, but then, I'm nearly blind as well as autistic.



# Listen – Don't just hear!

Listening is not the equivalent of hearing. Listening is an active response to a speaker; the act of making sure you are satisfied that you understand what they're saying.

Now – guess who some of the worst "hear but don't really listen" offenders are? Neurotypicals! Yeah – those folk with all their sympathetic and empathic skills!

How come? Well I reckon neurotypicals, when talking to other neurotypicals, express themselves partly by the words they use, but also by the tone, stress, facial expressions and body language. Add to this the fact that when a neurotypical doesn't really get something, they have the whole "I'm not getting this," vocabulary of body language to convey it.

This is why neurotypicals seem to communicate so effectively, and we're left largely outside the whole show.
Hence the need to develop really acute listening skills. Most of us on the spectrum – however smart –are inferior to an average neurotypical when it comes to decoding all that body language stuff; we rely on the spoken word both to understand and convey our meaning.

If a neurotypical is telling you something which you need/want to follow, make sure you actively engage with it – stopping them and asking them for clarification when necessary.

Treat the procedure like reading a textbook. The best way to profit from a text book is to ask questions while reading (Most modern ones have handy little selfassessment sections at the end of chapters anyway).

Don't worry too much if it turns out that neurotypicals haven't grasped what you are saying to them – it often turns out that way and it's their problem if they haven't made their lack of copon clear so long as you've been clear in what you've said to them.

### Summary

Listening is a skill.

Neurotypicals don't necessarily do it – they use body language etc. to interpret the other persons discourse.

Ask questions of the speaker as you would of any text book you read.

If neurotypicals don't follow what you're saying – and don't ask for clarification – then that's their problem.

# Listen to your body

This has got to be one of the most misleading pieces of information given out, particularly if you are on the spectrum.

In order to have any utility value, the statement would have to refer to "bodies" which gave their owners reasonably clear signals regarding their wants and needs. Unfortunately this is rarely the case, even for neurotypical bodies. Hunger, thirst, tiredness etc. are all signals which would be very useful to get, but which a lot of people on the spectrum don't clearly experience. You need to work out – logically – when eating, resting etc. are required, or you might find yourself lightheaded, weak legged and in the worst case scenario, dehydrated or undernourished.

Neurotypicals don't seem to fare much better – or, if they do get any of these signals, don't seem to have a problem ignoring them. Neurotypicals are famous for eating all the wrong stuff for example. So, if their body is telling them to do just that, then they would definitely be better ignoring it and using a little logic instead!

Obviously if you find yourself sweating and then shivering, every part of your body aches and your throat feels like it's on fire then trying to carry on as normal doesn't make sense, but neither does assuming that you'll get good quality feedback from your physical parts.

### Summary

"Listen to your body" is misleading – particularly if you're on the spectrum.

Hunger, thirst and tiredness are often not present, but neurotypicals who feel these signals seem to have problems interpreting as well.

Logic is a better bet.

Very strong signals of a negative kind are, luckily virtually impossible to ignore.

# Lists



If you don't already make lists, maybe you should start now. As BaronCohen observes, on the subject of autistic spectrum individuals:

"Their life is often governed by `todo` lists: they may even make lists of lists. Their domestic lives are full of self created systems."<sup>7</sup>

Properly used, lists can even get you the reputation of having a super – power memory when actually the only thing you need to remember is to look at your lists!

I generally have: "to buy" and: "to do" lists, plus a list of "to do when bored." This last list can be quite mundane (e.g. clean fridge) but mundane tasks are preferable to mundane boredom.

Ticking off each item as you buy it – or as you do it – can give a temporary little buzz (a buzzlet if you will). Also, of course, it helps you organize your day.

### Summary

Lists are a great way to organize your life.

Once you get into a "list habit" you only need to remember to look at your lists.

"To buy" and "to do" are the most useful.

Make sure you don't lose your lists or leave them at home.

<sup>7</sup> Baron Cohen, S., The essential difference: Men, women and the extreme male brain, Allen Lane: London 2003, p146.

## **Literal Mindedness – Adverts**



Despite their claims to the contrary, advertisements can be bad for you, in that the more literal minded you are, the worse they are. That's because adverts convey messages which are subtle and very sophisticated. They often work on two levels:

- 1. Manifest Visibly promoting a product.
- Latent Promoting a highly desirable lifestyle, which, coincidentally, users of the product are enjoying.

Now, no matter how smart you are, and no matter how much you pride yourself on seeing through any obvious attempts to get you to buy something with a brand name on it (especially when a cheap alternative exists), YOU ARE VULNERABLE to feeling excluded from the desirable lifestyle neurotypicals are portrayed as having.

Of course being on the spectrum can lead to a lot of loneliness and isolation, and a TV ad can seem like gazing into a window and seeing happy fulfilled people in an ideal world.

Ok, neurotypicals have a similar response to adverts, which is exactly why manufacturers spend vast amounts of cash creating smart little fantasy scenarios to broadcast. You – as an individual on the spectrum need to be extra vigilant

that you don't get dazzled by, and convinced of, the pseudotruth these adverts are latently portraying.

Consider an advert for washing powder – look closely at the kitchen depicted. Huge isn't it? Full of state of the art gadgetry. Clean! Clean! Clean! And look at the people in the advert – beautiful! Handsome successful fathers heading down the garden path to jump into a top of the range car – blooming beautiful mothers with deeply fulfilled expressions scooping a few designer garments into the washing machine, and (of course) healthy, happy, gorgeous children naughty enough to get grass stains on their Tshirts!

The same thing happens with beer adverts. Look at all those wonderful people in the bar as depicted. Some are having a great laugh, others are involved in deep, meaningful conversations, top quality live music is being performed/played, and a few couples are gazing at each other like it must be love at first sight.

Literal minded, on the spectrum individuals like us tend not to spend a lot on such products. Literal minded individuals like us, can, however, get a false impression of the joys neurotypicals enjoy which leads to feelings of loneliness and frustration as these unrealistic expectations are unfulfilled. Adverts are definitely NOT designed to make people on the spectrum feel this way – BUT THEY CAN.

Learn to recognise the latent content of adverts – like the whole idea of getting you to part with more cash for a brand name – it's based on illusionism.

### Summary

Adverts work on two levels – manifest and latent.

A lifestyle is portrayed as a background – it's actually a vital part of the advert.

Neurotypicals also find the lifestyle desirable – but people on the spectrum are even more vulnerable to feeling excluded and inadequate.

Learn to "read" adverts and see what the latest content consists of.



# Literal Mindedness – Jokes and Teasing

A lot of neurotypical jokes work because they're not literal minded. They can manipulate conversations so that literal minded folk like you and me will inadvertently make them laugh.

How often have you answered some neurotypical's question and found them falling about laughing "at" you and not "with" you?

Generally, insecure people go for cheap laughs at the expense of the literal minded. What I fail to understand is when someone you thought you knew well, someone who is aware you are on the spectrum, does this kind of thing.

"Only teasing" is the usual answer they give when challenged.

Ok so making you feel miserable and frustrated is fine once you call it "teasing"? Great! Teasing, or so I'm told, is an neurotypical bonding behaviour. Neurotypicals "tease" each other and they bond. No, I don't get it, and I doubly don't get why those neurotypicals who know you're on the spectrum do it.

It seems to be a case of avoiding neurotypicals who do it, and accepting the fact that, even so, it will happen to you from time to time. Here are a few warning signs to look out for when a neurotypical asks a question:

- 1. Is the question unusual? Does it fit in with the rest of the conversation or stand out awkwardly? If it doesn't fit in beware!
- If some neurotypicals are talking to each other, fall silent when they see you, then ask you a sudden question – beware!
- 3. If you notice neurotypicals winking to each other then nodding in your direction, then looking at each other or covering up their smiles beware!
- 4. If neurotypicals precede a question by saying: "Hey! You're an expert in such and such, what do you think of..." Beware!

The trouble is that, if you're not used to having that many conversations with neurotypicals, you'll be pretty overwhelmed by the whole scenario and maybe miss a lot of this. Try your best to catch these warning signs and avoid being the butt of their jokes.

### Summary

Neurotypicals can exploit your literal mindedness for cheap laughs.

Teasing can be bonding behaviour for Neurotypicals. Learn to recognise the warning signs.

Accept the fact that, until you get used to neurotypical conversations, stuff like this is bound to happen to you.

### **Literal Mindedness – Proverbs**



Most people on the spectrum are literal minded, whereas most neurotypicals aren't. Neurotypicals love to sprinkle their speech with little tidbits of folk wisdom – e.g. "You can't see the wood for the trees" or "It's the thin end of the wedge."

Learning a few proverbs to use yourself is hardly worth the trouble. Generally there's a nasty little maxim for nearly every event in human life, but no way of knowing which of two contradictory sayings is the most appropriate. For example, consider the following example – Ted leaves Cindy at home while he goes off to fight in whatever war is on at that time. Is it a case of Cindy finding that:

Either absence makes the heart grow fonder? Or out of sight, out of mind?

Presumably if you observe Cindy and find she's moping about the place miserably then it's "a", on the other hand if she starts dating someone else then its "b".

The two sayings "a" and "b" have a predictive value of zero and can only usefully be employed in a retrospective description of Cindy's behaviour.

Now here's something for you to try which might give you a little innocent amusement. Next time some neurotypical uses a "saying" in conversation, tell them you're sorry but you don't "get" sayings – "So could you please explain to me exactly what you mean by that one?"

Trust me – a lot of the time they can't! They use these things because they have a vague idea they're appropriate – challenge them and they'll start: "Well, it's...er...it's...you know...it's like...er..." etc! Ok some people do use them with full knowledge of their meaning but some people are not the majority.

### Summary

Neurotypicals use "sayings" because they're not literal minded.

Sayings are hard for literal minded people to apply accurately.

If challenged, many neurotypicals have only a vague idea of what the saying means.

## Medicine



Ideally, patients take their medicine and say "Yes Doctor / No Doctor" and they don't ask awkward questions. Individuals on the spectrum rarely make ideal patients. In fact they are liable to go through internet, library or bookstore data collections and amass huge bodies of material on all aspects of their problems (much of it contradictory). If this sounds like you, please remember the following.

- Although it is possible, in a short space of time, to find out an awful lot about one particular body part or body system, you do not have anything like the detailed anatomical knowledge of a doctor. In other words, you don't have the bigger picture.
- Not only do doctors have this background knowledge, but they also have experience working with patients, i.e. the handson stuff you just can't get from textbooks.
- 3. Any books you read or websites you access will carry a certain amount of authorial bias, so, as you read, ask yourself questions like: "in what style is the article written?" In general, the more racy, emotional and vivid an article is (with lashings of adjectives) the less likely it is to be neutral and sincerely informative.

YOU HAVE BEEN WARNED!

So what do you do about taking medicine? Do you find the prospect distressing? Scary even? The best thing to do is ask the doctor questions like "Why, exactly have you prescribed this?" and "What side effects might occur?" Medication is a means to an end, not a punishment. Unfortunately many people on the spectrum can't really feel comfortable while taking it. Remember, the end this particular means is aiming for is your health.

### Summary

If you research your condition, don't get the idea you'll become an expert.

Beware of believing all you read – study style as well as content.

Ask your doctor about the medicine, preferably before going on search yourself.



### **Memories**

Neurotypicals love talking about their own past. They can chatter away for ages about stuff they did, how they felt when they did it, and how they feel about it now. They get excited and animated and it usually doesn't work if you try to butt in and talk about some nice factual subject that you happen to be interested in.

Obviously one reason they have such good autobiographical memories is because they continually go over and over all the stuff. Another reason is the emotional aspect of it. Strong emotion seems to act as memory super glue. What you feel strongly about at the time – sticks. What you still feel strongly about – sticks even harder.

Your own specialist subject probably works in the same way. You get excited, passionate even, about what you love. Only with you its facts and figures, with neurotypicals it's autobiographical.

Feeling left out is a product if this process. Of course you can fake an interest in what they're talking... and talking... and talking about... but faking is an exhausting stressor.

It is probably less stressful to just accept that it's not for you and make the most of conversations which you can, genuinely, contribute to. Damage limitation is better than damage.

### Summary

Neurotypicals love going over every detail of their autobiographical memories.

Emotion seems to act as a memory enhancer.

You may well feel the same about your own fact based specialist subjects.

Faking an interest when you don't have one is liable to lead to stress.



# Monotropic and Polytropic Processing Styles

Generally people on the autistic spectrum are monotropic processors, neurotypicals are polytropic.

Monotropic means you can do about one thing at a time – with concentration. Polytropic means you can do several. An example of this can be seen in the tradition saying that men are supposed to excel at the first, women at the second. Really? While this is a major generalisation and not all that accurate in reality, it's useful for describing the differences between monotropic and polytropic processing styles.

It's very easy to see how polytropic you are when something you're doing is interrupted. Neurotypicals can usually take an interruption or two in their stride, and get back to where they were before. Monotropic people on the spectrum just can't – or only with great difficulty.

You might feel better about the whole issue if you consider that the great names in virtually every field of human endeavour were pretty monotropic, achieving their fame by focusing on their area of expertise to the exclusion of other things.

### Summary

Monotropic means doing one thing at a time. Polytropic means doing several things at once.

Men and women are generally assumed to be divided in this way. Assumed – not proven.

Monotropic seems to be a characteristic of those who get into the history books.



# Noise

Noise can be a painful problem for people on the autistic spectrum. As Florence and Gazzaniga note:

"The visual and auditory systems are sensory systems. People who are operating above the ninetynine percentile in one of the sensory thinking pathways may feel things much more intensively than others but react to things that other people find ordinary."<sup>8</sup>

Try getting neurotypicals to understand that noise (and maybe a few other intrusive stimuli like touch or smell) torture you. They rarely get it. They usually think you are a fussy little so and so. I've had the experience of coming home, soaked like a bath sponge and miserably cold after being out for hours in atrocious weather, and someone will say "How come you can put up with that – when a little bit of noise drives you into a state?" Well the answer is, I'm not such a wimp as they thought – but noise – in my psychological makeup, is the equivalent of pain in theirs.

<sup>8</sup> Florence, C. and Gazzaniga, M. "A boy beyond Reach", Simon and Shuster: London 2006 p. 250

Anyway to return to the issue – I'm sorry to say that I don't have a solution to the noise problem. Avoid or endure are about the only ways to deal with it. However, let's have a look at some of the major noise causers and a few alleviation strategies you might try.

There are about 3 big noise types:

#### Outdoor.

#### Indoor.

#### Internal.

Of these I'd put 3 down at the worst and 1 as the easiest to deal with.

#### Outdoor

These are noises that impinge from the world at large. Traffic accounts for a lot of it, so try not having important conversations on busy streets – way too distracting. Bear in mind that if the busy street is wet after rain, then the noise is far, far worse.

Air traffic can be very, very noisy – but the average plane comes, goes and is gone. A marvellous, beautiful state of the art house which happens to be built near a major airport – or under one of the airports major flight paths – will always be uninhabitable. If you're in the position of looking for a place to stay – bear this in mind! Also – hotels beside airports may be convenient but are also noisy.

If you like a walk in the park or botanic gardens, avoid weekends and bank holidays – that's when neurotypicals with their noisy children take over. A rainy day is the exception, but you'll only get yourself all wet.

If you're in the position of buying a permanent home, a trip to the civic planning office is a good idea – they'll be able to tell you what new developments are likely. No point ending up somewhere a motorway is about to be built.

Back yards can be sources of noise. Not only do neurotypicals own incredibly noisy D.I.Y. and gardening equipment, but they can't apparently use any of it without the radio blaring away at full blast. Rarely do they use anything with headphones. Avoiding the garden when this happens is about the best option. Usually weekends are the noisiest times.

#### Indoor

Most indoor noise comes from neighbours. The ideal autistic spectrum dwelling would be detached. Semidetached or end of terrace would be next best. Apartments are usually the worst – not only are the neighbours on either side but they're above and below as well.

Sound proofing? Trouble is there's sound proofing and "sound proofing." The real thing does exist, but has to be installed by a specialist firm and costs big bucks. Recording studios have it. "Sound proofing" on the other hand usually consists of something like a sheet of polystyrene in behind the plasterwork. You – with your noise sensitivity – probably won't even notice the difference. Beware! Test out any place that advertises as sound proofed to ensure that it actually is, you'll be very lucky if it is. Double glazing is pretty good for dealing with draughts, and that's about it.

By far the worst noises from neighbours are impact sounds: People banging, stamping, shifting bits of furniture, etc. These noises find it easy to transfer right through walls, floors and ceilings.

TV or music isn't as bad – unless they've got a mega bass system – in which case it sounds like impact. You'll probably only hear the bass line anyway.

Noise is far less intrusive if you have your own noise going on at the same time. I don't mean start a war with the neighbours – you're a bit too vulnerable to try war of attrition tactics – but, psychologically speaking, having to attend to something you want to hear can defuse the unwanted intrusion.

Headphones can be a good idea – but you'll probably find that something big enough to cover your ears completely is necessary.

Ear plugs are also useful. You need to talk to a pharmacist about the most suitable type. Like shoe sizes they come in assorted grades of noise reduction. Libraries, oddly enough, can be harder to read in than noisy café's. A quiet place with one or two talkers seems, psychologically to be harder to cope with.

#### Internal

Lie down on your left side and get acquainted with your heartbeat. Fun isn't it? You might never be able to do this – you might have to lie on your other side or your back... and then again, sometimes the "boom boom" might not bother you.

The pillow and the mattress on the bed can scratch or squeak or rustle, and again sometimes they'll be a torment, other times easily ignored.

Generally the early hours of the morning are the time your senses – hearing especially – are most acute (Yeah – wonderful isn't it? Just when you'd like to be able to rest...).

Ear infections are another noisy manifestation. Infections like Otitis media and temporary tinnitus (ringing), as well as normal sounds like papers rustling or machinery grinding can all occur. Don't forget your good old pulse – a tiny swelling deep inside can cause a blood vessel to be pressed against something and you'll get "boom – boom – boom" all freaking day (So wash those earplugs!).

Don't assume neurotypicals will get it if you explain – stuff that really upsets them might leave you cold so it's a case of keeping calm, not yelling, and explaining as clearly as you can (yeah, really easy when you're asking them to turn some gadget from hell DOWN!).

### **Summary**

Noise and the autistic spectrum don't get on well. Neurotypicals find it hard to accept and think you're over

reacting.

Outdoor noises are easiest to avoid or endure.

Don't try talking sense on busy streets and beware of airports.

Back gardens give neurotypicals a great place to make noise in.

Indoor noises come mainly from impacts. Sound proofing is rarely the real thing.

Making noise of your own often takes the sting out of someone else's.

Earplugs must be kept clean.



# **Overwhelming landscapes**

Whether they are natural landscapes or cityscapes, whether they're lovely or ugly, you can find yourself in an unfamiliar landscape so oversaturated with visual stimuli (and audio

too if it's a cityscape) that you almost get "stuck"! By "stuck" I mean so jammed up with the incoming data flow that you can't process it properly and you go into an overwhelmed state. You may not be able to move or speak or close your mouth or stop staring or, if you're really megastressed, you may start yelling, rocking or crying.

So what can you do?

Try this tip and focus on some details: if it's a natural landscape, go for plants, trees, stones; if it's a seascape, go for shells, rock pools, wave patterns; cityscapes provide road signs, street signs, neon, crossing signals, mail boxes, hydrants, etc.

Often you'll find that once you've picked out items of interest and are concentrating on them, then the rest of the stuff assumes a "background" status and isn't overwhelming.

#### Summary

Unfamiliar landscapes can overwhelm you. You could become physically affected.

Try fixating on several small items of interest.

This often enables you to process the landscape as foreground and background and not be overwhelmed.



### Perfectionism

It's a tough one. Most of us on the spectrum are perfectionists, and it's an uncomfortable way to be; failure is unbearable and, no matter how successful your successes are, the satisfaction is short lived, as it's off to try and do something else perfectly!

Neurotypicals have a great way of dealing with perfectionists; they say "You don't have to be perfect!"Maybe it actually works for neurotypicals, but it never did for me, so what I suggest is that you go on striving away for perfection, but that you try recategorizing "failure". When stuff goes wrong or when it doesn't go as planned,

just classify it as part of a vital stage on the road to getting it right.

Practice this technique and you may find the sting of failure isn't so bad. Notice that I didn't claim that failure won't sting – it always does but if you can get some of the venom out of it then you won't need such a big recovery time, and so you can get on with planning your next move towards perfection.

### Summary

Failure can be excruciatingly painful for a perfectionist.

Neurotypicals don't seem to really understand the problem.

Try tackling failure by categorizing it as a necessary evil on the road to perfection.

# **Personal Space**

"Personal space" refers to the amount of a gap people like to have between themselves and those they talk to. Generally, people born and brought up in the country require a lot more space around them than those brought up in the city. By and large people on the Autistic Spectrum like space, wherever born or brought up. Unfortunately you might often encounter a mismatch between your own idea of personal space, and that of the individual you're talking to. If this happens try and deal with it behaviourally- by backing away a little, rather than actually talking to them about it.



# **Politeness**

It's a case of being polite at all times and in all cases without exception. Even if you're dealing with someone you'd class as an enemy (and even when they know how you feel about them), politeness is far more impressive than a slagging match.

So, what's the easiest way to be polite? First of all, if the person you're talking to has a title – academic, peerage, clergy or army use that. They may well say 'Oh just call me Jim/Alice etc.' You then have permission to do so.

Some people default to: 'Sir', 'Madam','Ms'. You can do this yourself, but I personally see these monikers as alienating devices, therefore I neither use them when talking to others nor do I like being addressed in this way. It strikes me that there are enough alienating devices at work in society without us reinforcing them.

Holding doors is another positive polite thing to do. Have a quick look as you open the door for yourself and if anyone is close – hold it. This nearly always produces a smile and a 'Thanks'(Another 'antialienation' device.).

Giving up your seat on public transport for older or disabled people is a good thing to do – but don't feel awful if the whole public transport scenario is so intimidating that you simply can't.

To be honest, it's pretty easy to spot ways of being considerate if you look around. A lot of the time you'll probably be stressed out and unable to do this, so make the most of any opportunities you get.

### Summary

Be polite at every chance.

If you know someone's title use it – unless they tell you otherwise.

If you think of it – hold doors.

Don't beat yourself up if you get so uncomfortable in a crowd situation that you don't remember to be polite.





### **Problems**

Writing them down can help solve them! If you write it down you do two things with it:

You have to transform it into readable language. A lot of grey areas and vague bits can suddenly appear far more manageable once this is done.

By disembedding the problem from yourself, you acquire distance from it. Distance enables you to use your critical faculties, to view the problem from different angles – in other words, to see it as a 'something' which, like a job, can be worked at.

Spending the time to write down your problem – or typing it if this feels more comfortable can, in the long run, save time. Walking around with an unsolved, unexamined mess inside achieves little except frustration.

Another useful thing about writing down problems is the fact you have made a record of something which you can return to. A walk taken, some TV or a movie watched, a book read or several computer games later you may find your feelings towards the problem have altered for the better.

If this does happen you are already in a more powerful position with regard to the original problem – you can now see that part of it was how you felt about it. A problem, minus your negative attitude, is still a problem – but a much smaller one.

### Summary

Write down problems; this objectifies them and frees you to examine them from different angles.

Once written down – leave the problem and do something else.

Often giving yourself a break will result in a more positive attitude.



### **Public Transport**

If at all possible, try to avoid buses, trains, trams at rush hour (8am to 10am and 4pm to 7pm). Sitting upstairs on an uncrowded doubledecker can be very enjoyable – the same journey on a crowded one can be quite an ordeal.

If you must travel at rushhours then try to sit near the front if it's a bus. For some reason I've never worked out, extremely noisy, rowdy passengers always head for the back seat (up or down stairs).

You can try earplugs, or your own choice of music on the headphones, but you may still find the proximity of so many strangers a daunting experience.

Try sitting on the outside of the seat – this works especially well upstairs – people coming up the narrow stairway often just give a quick glance before finding a seat – it you're on the outside, chances are they assume both seats are occupied.

Taxis can provide a viable alternative. Obviously they can be pricey, but they can take the stress out of a long or late night journey. Used sparingly they could work quite well, since most drivers quickly figure out whether you want to talk or not.

If you do want some entertainment in a controlled environment, then ask the driver if he/she has driven any famous people? You often hear very interesting and amusing anecdotes. Taxi drivers are also great at telling you useful stuff about where to eat and visit if you don't know the town very well.

### **Summary**

If at all possible – avoid rush hour.

Upstairs outer seat often ensures a degree of privacy.

Taxis, though pricey, might be the less stressful option



# Relationships with married people of the opposite sex

Trust me - this can cause megaproblems!

A typical scenario could go as follows – a married lecturer of the opposite sex seems genuinely interested in you and your work. You assume you've made a real friend and act accordingly. Then one day their husband/wife comes into the picture. Fine, you think, let's all be friends!

Great idea! Unfortunately, it rarely works out that way. The husband/wife often sees you as some kind of a threat, and even if you try the "I'm autistic" approach, they just don't get it and continue to act hostilely. Now, if your relationship with the lecturer takes place only in College, then husbands/wives are rarely on the scene and won't really have much to do with it. On the other

hand, you may get invited to the house which, as you can guess, might lead to major problems.

My advice is – if you become friendly with a married person of the opposite sex then make sure the spouse is OK with that. Make friends with them too – and if this just isn't working then back off. Don't accept invitations to the house or go out socialising with them – it can lead to all sorts of stressful complications.

### Summary

If you are friendly with a married person of the opposite sex, try to keep it within the boundaries of College.

If possible make friends with the spouse.

If impossible then keep the friendship purely nonsocialising.



# **Routines/Novelty value**

Routines are great. Routines act like a psychological exoskeleton, allowing you to function away happily while providing a scaffold to your day to day existence.

Now here's the paradox; when you enter a new situation – going to college for example – the novelty value kicks in. Novelty value can often, temporarily, cause you to behave in ways you wouldn't normally behave, in your case, unautistic ways. However, as Martin Delphos notes:

"Novelty gives way to uncertainty, and any person on the autistic spectrum is likely to become anxious, "they want to know what is going to happen minute by minute."<sup>9</sup>

Don't experience a massive "novelty – value sugar rush" and assume that going to college (or whatever) has changed you into someone no longer on the spectrum. If you found it important and helpful to have routines for your everyday life, then you can be pretty certain you always will.

The best move is to utilize what your new situation offers and build a daily timetable around it. Neurotypicals seem to get on ok with big grey unplanned

<sup>9</sup> Delphos, M., "A Strange World Autism, Asperger's Syndrome and PDD NOS", Jessica Kingsley: London 2005. P 38.

areas in their day – fine – but for most of us boredom, frustration and downright misery are a more likely outcome (particularly if you're hyperactive.) Splice things like walking, shopping, private study, listening to music, eating, going to the cinema etc. alongside lectures and seminars into your schedule.

It's generally better to have set tasks on a list which can be ticked off as completed. You might not feel like a walk – good for you as you know it is – but a walk to the shops gives the exercise the extra purpose, and correspondingly, a greater feeling of satisfaction once you have done it.

### **Summary**

New situations can make you feel like a new person - temporarily.

If you needed everyday routines before the new situation – you'll need them again.

Try taking the best of the new situation and working it into your routines.

Unstructured time might suit neurotypicals but might not you.



### **Sensations and Sensationals**

I personally find most of these things a big problem. They definitely do not seem to correlate with the sensations as experienced by neurotypicals. Many people on the spectrum have different thresholds and, I suspect, many others have the same awkward sensory feedback that I get. Some of the sensations I've felt are, in my opinion, much much worse than any pain I've felt. The problem is how shall I describe this so that you can figure out whether something is goingon with you?

Try making a list of unpleasant physical sensations. What have you got? Pain obviously, which you may be able to divide into sharp acute pain / dull aching pain...then what? Nausea, dizziness, too hot, too cold, needing to use the bathroom, loud noises, etc. Ok, now I'll try, making it up as I go along, to convey some of the other stuff, namely the "sensational."

There are a few associated with food and eating. One of these is being full. Not necessarily too full, just full. Just having the presence of stuff inside, I don't like

this sensation. As I pointed out, I don't get hungry so I have to go from being nice and swept out and empty to being a processing factory for food, especially things that take quite a bit of digesting, like meat.

I dislike having material passing through and being broken down and sorted out and all of the other processes that go on, because "I feel" a lot of it. I haven't really come across this kind of thing in neurotypical accounts. Either it is solely an autistic phenomenon (or maybe just me) or, maybe neurotypicals only verbalize stuff like that when it goes wrong?

Alison Morton Cooper tries to explain some of this:

"The neurological threshold for sensory processing is likely to be idiosyncratic in a person with autism, given the biological basis of brain pathology. Hence a low threshold (i.e hypersensitivity and overreaction) may occur for some sensory inputs, while on a high threshold (hyposensitivity/underreaction) may be seen in response to others. These can affect different senses differently, so that a person who is very sensitive to auditory stimuli can, conversely, be underreactive to other stimuli that would be painful to others. While some stimuli may be filtered out, others may predominate and cause fear and a "fright or flight" response"

She also talks about pain specifically:

"Pain may be felt acutely and cooperation withdrawn. Conversely, the person may appear to have little reaction to what most people would seem quite painful. But a person who seems either impervious to or hypersensitive to pain in one situation will not necessarily react in the same way the next time. "Selective receptivity" may mean that the person responds to something else in the environment instead. Pain reaction may also be delayed or may be perceived in another part of the body"<sup>10</sup>

### Summary

Sensations are hard to describe in neurotypical terminology

Sensations associated with eating and digesting can be very unpleasant.

Pain can be experienced by people on the spectrum quite differently from neurotypica

<sup>10</sup> Alison Morton Cooper, "Healthcare and the Autistic Spectrum" London. Jessica Kingsley. 2005. P19



# Volunteering

Volunteering is a great way to pass time, help others, improve your CV and generally feel like a nice person, but be careful what you sign up for. Lots of volunteer programmes may be totally unsuitable for people on the spectrum.

Having watched a few movies like "Dangerous Minds" you might imagine doing grinds for inner city kids is a great way to change their lives for the better. However, once you experience the reality of such a prospect you might find yourself dropping out after one session.

If you don't get on well with noisy, cheeky kids then think again. Younger age groups, toddlers for example, might be a safer bet – but it's pretty hard to get onto programmes involving preschoolers – these days, vetting procedures can resemble CIA recruitment, so don't be amazed if you're on the bottom of a very long waiting list.

Working with groups of people with disabilities might be a more realistic option, particularly if they're of a similar age group to your own. Most young people who grow up as wheelchair users or registered blind will be deeply grateful to meet someone who does not: Treat them as though they were made of glass, and Talk about disabilities.

You might well find a lot of common ground since having physical difficulties means having to find creative solutions to everyday problems, and generally young people with disabilities are very mature and understanding – your place on the spectrum might seem as though it doesn't have any relevance when you're with them.

The other group which I would recommend are older people. A lot of these are either enduring a physically restricted existence in their homes, or being cared for in nursing facilities. In either case, they welcome interesting and enthusiastic people who can talk to them, listen to their – often fascinating – reminiscences, help out with bingo, shopping, crosswords, letter writing, reading aloud or even join in nonstrenuous games like bouncing a ball or tossing a bean bag.

You could also try and join up with one of the volunteering societies in college, such as SUAS or the St. Vincent de Paul Society. You'd be working alongside people your own age, and as a rule of thumb most people who are interested in volunteering are very nice and understanding people. If you haven't done any volunteering activities before and want to get involved, it would be a good idea to try it with student societies.

### **Summary**

Be careful if you volunteer that you know what's involved.

Generally younger children are easier to get on with than school age ones.

Unfortunately, it can be very hard to get accepted on a programme for helping out with toddlers.

Young people with disabilities might be a better choice.

Older people can provide deeply rewarding and accepting friendships, but remember they are frail.



# Voting

Vote. Do it. My advice is- get yourself as well informed as possible, then make a choice. Don't assume that "All these candidates are as bad as each other so I won't bother!" Bother! The candidates – be it local, general, or S.U. elections- are not all the same -there definitely are pros and cons. Don't let inertia prevent you from reading up on the background issues, and definitely don't let inertia and the fact that it's raining prevent you from going out on the day. Guess what? All the parties get their own supporters out there voting!

Here's a handy little pro-voting one liner: "Bad politicians are elected by good citizens who STAY AT HOME!"

### Summary

Get informed about the relevant background stuff. Don't let general disillusionment prevent you from going to the polling station. (Or rain.)

Remember- all the parties, including the ones you least like, will have their supporters out voting.

How do good citizens help bad politicians get elected?



### http://www.tcd.ie/disability/







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