

## What's this about?

Every so often, someone says, with perplexity, "I seem to be getting more autistic. I don't know why, and I know that doesn't sound possible, but it seems to be happening."

Those of us who experience this are often surprised, because of the general perceptions that are out there about autism. It is viewed either as something stable, or, as in the writings of Liane Holliday Willey, Temple Grandin, and other authors, as something that fades away with age.

The fact that some autistic people *lose* abilities with age is well-documented, but it is not always discussed in clear ways. It is clouded by terms like *regression* (which implies that loss of skills is growing backwards), *functioning level* (which implies that all functioning is affected at the same level and that this can be measured in a linear fashion), and *more autistic* (which implies similar things to *functioning level*). When autistic people ask organizations about it, we often get confusing answers — for example, when I asked one representative of a major autism organization about being an autistic person who lost some movement skills in adolescence, she said, "Yes, there is such a thing as late-onset autism," as if I had not been autistic before this happened.

This has been writing itself in my head for a long time. It started writing itself *on paper* about a year ago or more. I wish I'd had a list of things like this a few years ago, and it's based on what I'd like to have known. I hope it will be useful to other autistic people. It is intended to give people a list of starting points to understand what is happening to them. It *is*, though a *starting point* — more heavily focused on *what is going on* than what to do about it. This is because there are still more questions than answers, and because answers vary from person to person. I am providing answers that come with more questions. It is also intended to be practical first, medically perfect second — some of the research or opinions linked to from here may be largely wrong, but may be a starting point to looking at other things.

I hope it will be useful to other autistic people, who are the primary audience. Personal information is only disclosed because I hope someone in a similar situation would find it useful. This page could also be useful for non-autistic people who have an autistic person in their lives who is acting more stereotypically autistic than they had been, but they are not the people I'm directly aiming this at. It is not, and probably cannot be, exhaustive, and there will be things I cannot cover in here. However, I do try to cover everything I can think of, including things that are relatively uncommon. If something doesn't seem to fit, or seems obvious, feel free to ignore it. I will try to improve and add to this as time goes on.

I would like to cite my sources for this information, but unfortunately I don't remember most of the sources. I have included a list of further references at the bottom, but a lot of this is consolidated from years of information-gathering in which I did not frequently take note of where I found the information. New sections of this document contain the date they were added.

**Note: If you are fairly new to knowing you are autistic or thinking about being autistic, you might want to read the section about [learning that you are autistic](#) before anything else.**

## What could be going on?

Note that in some of the cases below, neither the situation nor the result is necessarily negative.

### Aging

When non-autistic people age, they often lose some of their former cognitive abilities in a subtle way. When autistic people age, what would be subtle in a non-autistic person can cause extreme-looking differences in an autistic person, because our hold on certain kinds of cognition is so shaky in the first place.

There has been very little study done on what happens to autistic people as they get older, but personal reports suggest that many common ways of dealing with the world as an autistic person can become less feasible with time. Thus, a person who has been working very hard to keep up with the non-autistic world may suddenly find herself slowing down and needing to do less of it. This can look like becoming more autistic, even when it's simply being less able to adjust.

### Basic physical needs

This may sound obvious, but to a lot of us, it isn't. If a person lacks food, water, sleep, and in some cases hygiene, they are not going to function as well. Autistic or non-autistic. If you are malnourished (which can happen even if you eat the right amount of food, if you're not eating the right kinds of food or if your metabolism is fast), dehydrated (which some fluids you drink can contribute to rather than solve), or sleep-deprived (which can happen even if you sleep a lot, if you have something like sleep apnea interfering with sleep), you are not going to function as well. It is a good idea to look into these basics before anything else — wherever possible, if you improve food, water, and sleep, you might see improvement.

### Being around other autistic people

For those of us who are echolalic or echopraxic, being around other autistic people can cause us to pick up mannerisms, phrasings, and sounds from others. When I lived around mostly non-autistic people, while I had autistic patterns of doing things, I was more likely to pick up non-autistic mannerisms to add to them. When I was in special ed, I picked up (without always realizing it at the time) mannerisms not only from other autistic people, but from at least one student with cerebral palsy.

There is something about other autistic people, though, that makes their mannerisms easier and more natural-feeling for me to echo than anyone else's — even when they are things I had not done before, they feel more right on my body. Some other autistic people have reported that being around other autistic people has a similar influence on them, and this has also been reported by Touretters.

*Note:* Some people see this kind of thing and say that it is exactly why autistic people should be kept away from other autistic people. I do not believe this. I do not believe that it is worse to have autistic mannerisms than non-autistic mannerisms, and I do not believe that autistic people make bad role models. I *definitely* don't believe that any of this is a reason to separate autistic people from each other or to encourage an autistic person to dislike being around other autistic people.

## Brain damage

Non-autistic people with brain damage often develop traits that bear some resemblance to autism. Since autism is developmental, our brains have already developed the way they are, damaged or not, so there are some differences. But if an autistic person develops significant enough brain damage, it could show up as looking more autistic.

Many autistic people self-injure by banging our heads. This can cause brain damage, especially if we do it frequently, very hard, or to the point of knocking ourselves out or causing minor concussions. Having a head injury for some other reason, stroke, or brain tumor can cause brain damage. So can the drugs and shock treatments (ECT) that some autistic people are given.

The [Traumatic Brain Injury Survival Guide](#) gives some information about how brain damage can change a person. Many of the same traits can be autistic traits, so having them does not necessarily indicate recent brain damage.

## Burnout

Burnout, long-term shutdown, or whatever you want to call it, happens generally when you have been doing much more than you should be doing. Most people have a level to which they are capable of functioning without burnout, a level to which they are capable of functioning for emergency purposes only, and a level to which they simply cannot function. In autistic people in current societies, that first level is much narrower. Simply functioning at a minimally acceptable level to non-autistic people or for survival, can push us into the zone that in a non-autistic person would be reserved for emergencies. Prolonged functioning in emergency mode can result in loss of skills and burnout.

With some diseases with long-term effects (and I am not suggesting that autism is a disease), it is the people who tried to ignore the long-term effects and "act normal" who often burn out, probably because they are drawing on emergency reserves to do so. There is a high chance that autistic people who attempt to ignore the fact that they are autistic and act like non-autistic people are subject to the same kind of burnout, or even autistic people who push themselves too hard in general without trying to look normal.

The danger here may be obvious: It may be the people most capable of passing for normal, the most obvious "success stories" in the eyes of non-autistic people (some of whom became so adept at passing that they were never considered autistic in the first place), who are the most likely to burn out the hardest and suddenly need to either act in very conspicuously autistic ways or die.

To the outside world, this can look as if a forty-year-old perfectly normal person suddenly starts acting like a very stereotypically autistic person, and they can believe that this is a sudden change rather than a cumulative burnout eventually resulting in a complete inability to function in any way that looks remotely normal. The outside world is not used to things like this, and the autistic person might not be either. They might look for the sudden onset of a neurological disorder, or for psychological causes, and receive inappropriate "treatments" for both of these, when really all that has happened is massive and total burnout.

This can also look much less spectacular, or be much more gradual, and it can happen in any autistic person. Sometimes, with more supports or a change in pace or environment, the skills lost

come back partially or totally. Sometimes the loss in skills appears to be permanent — but even that can be somewhat deceptive, because sometimes it is simply that the person can no longer push themselves far beyond what their original capacity was in the first place.

Sometimes this kind of burnout is what leads adults to seek diagnosis and services. Unfortunately, many service systems that would otherwise support people in their own homes, cater only to people who were diagnosed in childhood, and will look at someone with a very good neurotypical-looking track record of jobs, marriages, and children with suspicion. They need to be made more aware of this possibility, because there's a high chance that an adult in this situation could end up jobless, homeless, institutionalized, misdiagnosed, given inappropriate medical treatment, or dead.

People training autistic children to look more normal or refusing to tell their children they are autistic also need to be aware of this possibility, because this is the potential end result ten, twenty, thirty, or forty years down the road. This is one of the biggest reasons for teaching us to learn and grow as ourselves, accounting for our strengths and weaknesses rather than as counterfeit neurotypicals.

## Catatonia

While this is more of a sign than a cause, it is worth mentioning here. There seems to be a subgroup of autistic people who develop an increase in manifestations of catatonia during adolescence or early adulthood. This can happen to different degrees, and it can come and go. The cause is unknown at this time, and most researchers have focused on movement, although some autistic people have found that sensory issues are affected as well.

Catatonia is a much broader term than the stereotype of sitting in one place in an odd posture doing nothing, and it is not synonymous with hallucinations or something. It is a word used to describe any of a number of unusual movement patterns, including but not limited to freezing in a position from anywhere from seconds to days (and either being immovable or bendable into any position a person wants to bend you into), echolalia (imitating others' speech), echopraxia (imitating others' movements). Many of these traits are already present in autism to begin with, so it is thought that in some people, these traits may amplify over time for some reason.

Lorna Wing and Amita Shah have written a paper on the subject of exacerbation of catatonia: [Catatonia in Autistic Spectrum Disorders](#). While they have written about people in which this is extreme, they note that there are other people who have similar movement issues but who did not have enough of them to qualify for the study.

*Note:* It should be noted that catatonia can be easily exacerbated by neuroleptic drugs, which interfere with the process of directly connecting thought to movement, and that lethality of such drugs among people with catatonia is much higher than in the general population. If you develop signs of catatonia while on a neuroleptic drug (prescribed as "antipsychotic" and sometimes antiemetic), *seek medical care immediately*, because this can sometimes be a sign of a potentially-fatal reaction.

## Change in Environment or Routine

Here are some of the more major examples of this category:

- Getting married or divorced.
- Getting fired, getting a job, or changing jobs.
- Promotion or demotion at work.
- Changing schools, dropping out of school, going up or down a grade in school, or entering school.
- Moving to a new house or apartment.
- Moving out of or into an institution.
- Death in the family (human or non-human).
- Making a new friend or losing a friend.

Change can be a lot more subtle, though. It can be someone moving your stuff around the room, or hanging a new picture on the wall. It can be changes in weather, climate, or society over time. Since having a regular routine is one way autistic people deal with the environment, when that routine is disrupted, then autistic people often rely on *other* autistic ways of dealing with things. We can also have less energy to deal with things and thus look more outwardly autistic. Depending on the person and the nature of the changes, this appearance of being "more autistic-looking" can be temporary or long-term.

## Compartmentalized learning style, or trouble generalizing

[Added 15 May, 2004]

Some autistic people learn things, but have trouble accessing what we learn out of context. For example, if you (as I did) learn right and left facing a certain wall in a certain room, you might be unable to tell left from right outside of that room. Then, as you learn to generalize it a *little* bit, you might learn to tell left from right, but only when you are facing east.

If you learn a skill in one environment, you might think you have mastered it. And you might be right — in that environment. But then when you leave that environment, or when a small aspect of that environment changes, you might end up disoriented and unable to do something that you seemed very good at before.

Many autistic people know a *lot of things*, or know how to *do* a lot of things, but have a lot of trouble bringing that knowledge out on command. We might rely on triggers in our environments to help us do those things, but in the absence of triggers, our minds might go blank and be unable to come up with the right answer or skill to fill the needs of the moment. We might have one set of skills and knowledge that we can use with ease in one situation, and a completely different set of skills and knowledge that we can use with ease in another situation. In some situations, we may be unable to get at much of this knowledge at all.

This can make for some interesting experiences with apparent loss of knowledge and skills, or even having to *relearn* the same thing over and over when we forget we've learned it, or need to learn it for a new context. I don't know how many times I've told someone I didn't know something, and then later had the knowledge they wanted triggered in a different context. If this happens to you in drastic enough ways, it can be essentially the same as losing a skill, perhaps forgetting you ever had it, and having to relearn it from scratch if you can relearn it at all.

As an example, I was, as nearly all children were where I was a kid, drilled over and over again in

what kinds of strangers to avoid. Like the kind who would lure you into a car with a toy. Yet as a twenty-something adult I was almost lured into a car by a toy. What stopped me was not that I remembered this was dangerous, but that I didn't like the people who were doing it or the fact that they kept touching me and talking about sex. I did not perceive what they might do to me, only that they were unpleasant. I *had* this skill, somewhere in my brain, but it did not come out at the appropriate moment, and it was days before I put things together enough to relearn this. I still do not know if it is in place enough that this could not happen again.

While what I describe is different from what happens in what gets called post-traumatic stress disorder (PTSD), it can definitely be amplified by PTSD. PTSD can involve mentally shoving certain terrible experiences into compartments where they hopefully won't be found easily, and it can increase a tendency to compartmentalize knowledge in general.

### **Deliberately adopting new strategies**

The ways that autistic people behave do not materialize out of nowhere in order to make us look strange. They have purpose to us, and may help us to deal more efficiently with the world than the way a non-autistic person would go about the same task. Often, many autistic people will independently come up with the same way of approaching a situation (some of these ways are so common that they make it into the diagnostic criteria). However, not all autistic people will come up with these things, or some will have come up with them and eradicated them so long ago they don't remember having come up with them.

This leads to the situation in which an autistic person who has trouble dealing with a situation may deliberately choose to approach that situation in the same way as someone she have met who is also autistic. This has the advantage of being more likely to suit an autistic person's brain and senses.

For instance, a commonly-described activity among autistic people is to carry a single object everywhere. Not all autistic people come up with this on their own, but it can be a very effective way of dealing with the increased load of sensory input and processing demands in new places. An autistic adult may see someone doing that and think, "Okay, if they do that and it works, I'm going to try it." They may then look "more autistic" because they are using an strategy that is more efficient for the needs of an autistic brain rather than a non-autistic one.

This can happen with nearly anything labeled an "autistic behavior," because autistic people behave the ways we do for a reason. A person may stop making eye contact because he wants to listen to what is being said. He may start moving his hands in front of his face to regulate visual input. He might start regulating the amount he interacts with people in order to avoid overload and burnout. He may not have thought of doing these things before, but after seeing them work for another autistic person, he may have adopted them and found them more useful than anything a non-autistic person could come up with. This is not a bad thing.

### **Disuse**

[Added 15 May, 2004]

Most people find that if they don't continually practise a skill, their ability to perform it fades. This can be the same for autistics, although it is not always the case. (It is not always the case for

neurotypicals, either, hence the saying "It's like riding a bicycle" to describe a skill you haven't used but that is not lost with time.)

Autistic people can find that if we don't do things for long enough, we forget how to do them. Even if they are not the sort of things non-autistic people forget. (I nearly needed training wheels after not using a bicycle for a few years.) This effect can be amplified if the skills in question are not only not used, but not desirable in a certain situation (such as assertiveness in an institution).

If you have not done something for a long time, there is a chance that you will have forgotten much of how to do it. (There is also a chance that you have *gained* ability to do it, which I do not understand but which has happened to me a lot with skills I leave dormant for awhile.) This can mean you have to relearn it wholly or partly, and it may not come back to your previous level of ability.

### **Dropping a facade or rebellion against a taught behavior pattern**

In those of autistics who either appear normal or try to appear normal, the facade of normalcy may be maintained by a set of precarious strategies. Anything that interferes with one of those strategies can cause large parts of the act to disintegrate.

A person may even be spending so much energy on these strategies that he does not have any energy left over to notice that he is acting. When the facade drops, he is left wondering what happened.

Other autistic people consciously say "Enough is enough," and stop expending a whole lot of energy trying to look like someone they are not, or doing things that they have been taught to do but which are useless to them. If you do this, be aware that what *to you* feels like you are the same way you always were but with less acting, to *other people* it can look like you've suddenly become a new person. This does not make it bad — in fact, it's important for people to be able to live life as themselves and not as an act — but the unpredictable behavior that others might have in response to this is worth preparation for where possible.

### **Drugs**

Any drug that acts on the brain can have an unusual effect on an autistic person, and amplify traits. It should be noted that I am not a doctor. The following descriptions are culled from both medical literature and the personal experiences of many autistic people I have known, read, observed, and been. There has not been a great deal of research into the exact effects of drugs on autistic people, but we can definitely have unusual reactions — underreactions, overreactions, and "paradoxical" (reverse) reactions being the most common. None of the things I am about to relate are true of everyone, although some are more likely than others. And I am only putting the things in here that could relate to an apparent increase in autistic traits.

Neuroleptic ("antipsychotic") drugs, including the newer ("atypical") neuroleptics, can increase problems with cognition and voluntary movement, can lower the seizure threshold (see [epilepsy](#)) and induce a motor restlessness (akathisia) that can result in increased stimming, self-injury, and aggression. They can also induce a condition called tardive dyskinesia, which results in involuntary stim-like movements and cognitive losses and is close to irreversible. These drugs can also cause

permanent changes to the shape of the brain, which are probably implicated in the long-term changes in cognition and movement. My father says that I have never moved the same — and that I look much more stereotypically autistic — since the first day I took Thorazine (chlorpromazine), and it has been eight years since that day, and four years since I stopped taking any related drug.

**[Note: If you are on a neuroleptic and develop catatonia, seek assistance immediately and consider discontinuing the drug in the safest way possible. That can be an early warning sign of a potentially fatal syndrome called Neuroleptic Malignant Syndrome (NMS). Even if you have an autism-related form of catatonia, this can be serious — in fact people with catatonia to begin with are more susceptible to NMS and to other adverse reactions to neuroleptics. Yes, I'm repeating myself, but this is life and death.]**

Antidepressants can potentially disinhibit us, making us more likely to act impulsively and immediately on thoughts. Some people may find that they are more hyper and stimmy. Some people, such as Dave Spicer on bit.listserv.autism, report that their sense of being behind a facade increases. Some people have found that their sensory issues get worse and find the environment more overstimulating, and others have found themselves more anxious or active.

Stimulants can increase anxiety, which can lead to an increase in the sort of things we do to alleviate anxiety. They can also increase movement in general, making us more stimmy or ticcy.

Sedatives can impair thinking, with all the possible things that go with that.

Anticonvulsants can impair thinking and perception. If this is happening to you with one anticonvulsant, it might be a good idea to ask your doctor or neurologist about other ones. I had to try several (including one that induced outright delirium) before I found one that was acceptable.

The strong anti-fungals prescribed by some doctors in the (nearly always mistaken) belief that an autistic person has a "systemic candida infection" can cause a person to become extremely sick, which can in turn cause all the things that can go along with being sick.

Some street drugs, such as marijuana or LSD, can increase sensory fragmentation, sensory distortion, distorted sense of time, speech problems, anxiety, and so forth. Autistic people have reported extremely varying and unusual reactions to these drugs.

## **Emotional state**

If you're in a bad mood, it can affect your ability to do things as much as being sick can. If you're in a long-term bad mood of some kind, that can have the same effect on your ability to do certain things as a physical illness. Even a very good mood, like being in love, can be stressful and reduce your capacity to do various things. Non-autistic people have a term — "lovesick" — that exemplifies the degree to which even a positive emotion can incapacitate people.

This means that if you are experiencing rage, depression, terror, love, hate, infatuation, or any other extreme emotional state, you could very well end up appearing to be more autistic than usual. Some people, though, find that they look less stereotypically autistic in these states, and that *calmness* and *being at ease* makes them look more stereotypical. For instance, if a person has been conditioned by fear into avoiding unusual movements, they may stop rocking when terrified and start rocking when calm again.



Trauma is an extreme emotional reaction to a usually-extreme negative situation, and it can cause significant loss of skills even in non-autistic people. If you have ever been in a situation where your life was in danger and that has changed you significantly, that is one example. If you have ever been abused (emotionally, physically, or sexually), whether by your family members, classmates in school, teachers, strangers, or staff, that can be another example. It is also possible that autistic people with some kinds of sensory sensitivities are more likely to perceive certain stimuli, such as being held down, as unbearably traumatic.

## Epilepsy

There are many forms of epilepsy, not just the tonic-clonic ("grand mal") seizures people are used to hearing about. Some forms of seizures can even take place while conscious, and alter perception in some way rather than causing a blackout of some kind. Not all seizures are in the right part of the brain to be easily detectable on an EEG, and not everyone can manage to have seizures in the laboratory when the EEG is taking place.

There is an estimate that 25% of autistic people develop seizures of some kind at some point during our lives, and this often happens at adolescence.

Some researchers have hypothesized that there are autistic people who develop seizures or subclinical seizure-like activity in adolescence and lose a lot of skills. A popular article by Stephen Edelson is [Autism, Puberty, and the Possibility of Seizures](#), although I make no claims for the accuracy of the part about vitamins and supplements and would not advocate experimenting on other people with them.

## Erecting a new facade

There is a subgroup of autistic people who get along in life by imitating non-autistic people. Imitation can become a habit. When they learn that they are autistic, or when they start becoming more identified with being autistic, they can almost reflexively throw up another facade: That of imitating themselves to the point of self-caricature, or imitating other autistic people in a fairly superficial way the same way as they always had with non-autistic people.

As noted elsewhere, it is also possible for autistic people to deliberately or accidentally adopt each other's mannerisms or strategies for dealing with life *without* it being a facade.

## Excuses or laziness

This is the section I am reluctant to write, because most of the people accused of doing this are not actually doing it, and too many of us have had to face these accusations to a degree that can even endanger our lives. But since it is a real possibility, it needs to be described. I just hope this doesn't cause too many autistic people to sit around questioning themselves to death, or too many non-autistic people to push autistic people beyond our capacity. Be aware that in the scheme of things, this is rare.

Some people and groups of people — autistic or not — have the sort of personality that is prone to making excuses not to do things they should do, to do things they shouldn't do, and to self-pity or public appeals for pity. This is not to be confused with sensibly rationing one's activities in order to

avoid cumulative overload, or with stating the facts about one's life or abilities. But it does happen. And people who are prone to doing this, who are autistic, will naturally drag autism into things. As they would anything else.

Unfortunately, most of us who are accused of doing these things really are not. If you are agonizing over this, please stop if possible — agonizing won't do any good whether this applies to you or not, and most likely it does not. If you are a non-autistic person ready to accuse an autistic person of doing this, be aware you could be *very* wrong, and cause a person a lot of damage in pushing them too far.

## Gaining or using new skills

It can be a normal part of even non-autistic people's development, that when a certain difficult skill is being gained, others are temporarily lost. In autistic people, this loss or disruption of skills can be longer-term or permanent, and more prominent than it would be in a non-autistic person. An autistic person who learns to talk may lose some social skills, an autistic person who gains some social skills may lose the ability to talk, and all kinds of other combinations of things. This may be a natural part of learning for some people, and in others it may be a sign that they're being pushed too far.

Many autistic people can only devote energy to one thing at a time. If you want to improve your ability to listen to people, you might have to give less eye contact. If you want to understand your surroundings without too much overload, you might have to rock and flap your hands more. When you're actually using *more* skill in one area, you might look more autistic to others because you don't have the energy to do things to look normal. See the section "Deliberately Adopting New Strategies".

## Habit

Autistic people can be very much creatures of habit, literally *needing* objects to stay in the same locations and routines to happen the same way every time in order to function. There is nothing necessarily wrong with this; it is similar to how blind people frequently need things to stay in the same spot in a room so they can find them.

When you get into a routine, and have been doing the exact same routine for thirty years, it becomes much harder to deviate from the routine than it was when you had only been doing it for a year. Smaller changes seem like bigger changes. Travelling away from the place you are used to can feel like chaos, and your ways of dealing with that chaos can seem more outwardly autistic to you or an outside observer.

If you are concerned about this, it might be a good idea to force tiny changes in routine every now and then, and gradually make them bigger. This may be impossible for some people, but for others it can help them maintain a certain degree of flexibility, even if it is much less flexibility than a non-autistic person normally has. In any case, it's a personal decision.

## Hormones

Hormonal changes can take place in a person's life for several reasons: Puberty, female menstrual

cycles, menopause, and other generally normal hormonal changes in people's lives. Some people will also end up taking hormone pills for a variety of reasons. Just as hormones can change a lot of things about non-autistic people, they can change things in autistic people. Some autistic people react to these times in our lives in fairly extreme ways, for some reason.

## **Increased developmental demands**

People — in general — are expected to follow a certain pattern of development. Autistic people rarely follow the usual pattern, and even when we seem to, there can be important differences. We are expected, however, to develop in a certain way, and the societies we live in are structured to the developmental standards of the non-autistic majority.

Because of this, our behavior may stay the same while expectations change around us. When I was six years old, curling up in a ball and hiding under things was something my parents called "curling up small". They thought it was cute. By the time I was a teenager it was considered pathological, written up as "regressing to the fetal position" in my medical records, and viewed by institution staff as attention-seeking. This wasn't a case of me becoming any more odd-looking, but a case of the expectations changing.

There are a lot of skills that people are expected to gain at different stages in life, that many autistic people only gain in a limited way, if at all. Sometimes we lack some very fundamental precursors to those skills, but this lack shows up in different ways in childhood than adulthood.

For instance, when I was a child, I could not clean my desk or locker. I was often kept after class to do so. I had poor sequencing skills and my perception of the world was so fragmented that even with the best of intentions and coaching there was no way I could get things into a semblance of order, and the only way I could get things even vaguely close was to take hours longer than any other child my age would have.

In the scheme of things as a child, this rates as "annoying".

Fast forward to adolescence and adulthood. The same sequencing and perceptual skills that were required in order to clean a desk, were also required in order to do what is expected of older people. Suddenly, without even having to lose any skills, I started to look a whole lot odder: A teenager who never bathed, never combed her hair, and wore the same clothes for weeks. An adult who could not grocery shop, take the bus, cook, eat, bathe, maintain a minimally sanitary environment, or remember that the front yard was not a toilet. This was not for lack of exposure to the means of learning these skills — my siblings learned them to a greater extent than I did — but for lack of having ever had the abilities that *precede* these skills. What was annoying as a child was life-threatening as an adult, not because the skill changed, but because the expectations of the environment changed.

There is another side to this as well. With increased demands usually comes an increased attempt to meet the demands of the environment. This can overtax an autistic person, with the usual kinds of results: Overload, burnout, or loss of other skills.

## **Institutionalization**

Institutions can affect non-autistic people in certain ways that are very characteristic. They can

create an inability to function without specific routines and rituals. They can create passivity and the inability to do anything that a person is not directly told to do. They can create disorientation when outside of a small familiar area. They can create an inability to approach people directly. They can cause a person to lose previously acquired skills for coping with the outside world, in favor of skills that are more adapted for the current environment and that can be harder to lose. Trauma, isolation, or sensory deprivation can cause a person to rock and stim. Prolonged isolation or specific social situations unique to institutions can cause detachment from other people.

These things can happen to autistic people too, and we've already got some of those traits.

There are many kinds of institutions. When I first got out of institutions, I didn't believe I had ever been institutionalized, because none of the places I was kept called themselves institutions and I was very literal. Institutional situations can occur in hospitals, group homes, state schools, residential schools, nursing homes, and similar places. Similar things can happen if you are in a highly structured environment such as the military or a monastery or convent.

Aside from these things, some supported living arrangements can be institutional despite their claims otherwise, some parents can run their homes like institutions, and some behavior modification programs can cause similar effects. Special education schools, day programs, and sheltered workshops can have this kind of effect too. And with just about any place that has an isolation room (often known as a "quiet room", "seclusion room", etc.), or any place where you have been deliberately locked in a closet or cupboard (or any other small room; some people lock people in bathrooms) by someone else for any reason, there is a fair bet that the atmosphere is the same one I'm describing. Jails and prisons, prisoner-of-war situations, and abusive relationships can also have this kind of effect to varying degrees.

At any rate, living in this kind of situation can increase certain autistic tendencies, whether to adapt to the environment or because of sheer terror resulting from bad experiences.

If you want to read more in terms of theory about the way these places can affect a person, I would recommend *Asylums*, by Erving Goffman, which explores the effects of not only traditionally-defined institutions but also boarding schools, the military, and monasteries. Some of the more level-headed literature out there on destructive cults (which need not be religious in nature) is not bad either, because it describes both the ways in which people can be confused into self-doubt, and also the loss of everyday living skills that comes from living in a place in which everything has been defined and controlled for you. There is plenty of such information on the Internet, and one book I have read on the subject (that had some pretty good ideas) was *Combatting Cult Mind-Control* by Steven Hassan. It should be warned, however, that some of this kind of literature has a psychiatric or religious slant (or both) that may not appeal to some readers.

## **Learning you are autistic or perseverating on autism**

It is *very common* for people to appear more overtly autistic when first learning about autism. This can be for any number of reasons, most of which relate to other categories here. This period can last anywhere from days to years. I heard one person describe it as "the post-diagnostic regression".

Upon learning you are autistic, you might feel relieved of some degree of pressure that stems from having to push yourself hard and not knowing why. Without even meaning to, that relief can cause

you to drop your guard a bit, or even be unable to continue pushing yourself as hard now that you know why you were doing it. You might spend more time around autistic people, learning autistic ways of dealing with things and possibly picking up some of their mannerisms. Behavior you have suppressed for a long time might re-emerge now that you know it's not caused by being stupid or something.

You might also be so scared that you won't be accepted as a real autistic that you start, as one person who had done so once said to me, become a "super-autistic", claiming every autistic trait you come across whether it applies to you or not. You might imitate yourself to the point of self-caricature. You might stop doing things you like doing because they don't seem autistic enough or don't conform to the stereotypes you've heard of autism. You might try so hard to regain your "lost self" that you end up creating a new facade. You might act like the autistic people you've known, figuring it's safe to act like them but not safe to do anything they don't do.

These things *are fairly normal* when you're learning about autism, and are not shameful. They may, in the long run, lead to self-doubt when you realize you can't tell who you are from all the stuff you're now saying and doing because you want to be sure you're really autistic. This can be a vicious cycle: First you doubt yourself, then you do something autistic-seeming, then you wonder if you were acting, then you doubt yourself, then you act, then you wonder if you were acting, and so forth. This doubt does tend to settle after awhile, and so does the acting. In fact, they often settle at the same time, when you become more comfortable with yourself and with the idea that you are autistic.

Perseverating on autistic traits, as many do immediately after discovering autism, can also temporarily amplify them. If they are *negative* autistic traits, you might want to find another perseveration. Focusing entirely on a few traits isn't always a great thing to do long-term (and it can also create a sort of "autism hypochondria"), although if done in the context of the rest of you it can be a good route to self-understanding eventually. You are not likely to understand your relation to autism with any degree of completeness until after you have thought about these things for awhile, though. This knowledge requires time to observe and adjust to it. There is no need to rush it.

There can also be a good deal of emotional turmoil when you learn you are autistic, and that can affect you the way most strong emotions do. This may stem from things related to the diagnosis, or even feelings of guilt or shame for perseverating on autism, *being* autistic, or doing things in order to be more "acceptable" as an autistic person. There can be a lot of fear that you aren't autistic, or that you *are* autistic. The emotional turmoil can take awhile to pass, but it does seem to pass for most people.

It is likely that as you become more comfortable, you will look more stereotypically autistic *in the ways that you are actually autistic*, and less stereotypically autistic in the ways that were results of stress or other factors described above. There are many myths about us being passed around. Many of those myths originated from one autistic person overgeneralizing about themselves, or outside observers making unwarranted assumptions. It is important to remember that *no autistic person on the planet* fits every stereotype of autism.

## Looking for a lost self

Many autistic people who have pretended to be normal for a long time, who have undergone extensive behavior modification, or have read any of the literature by the many autistics who have done so, might decide that there was a "real self" that stagnated inside of them while all of the acting or behavior mod stuff happened. This might cause people to, in various ways, go looking for that real self.

This may involve trying to remember the way the "real self" behaved, and trying to dig back through time to find out when the "real self" went into hiding. If a person remembers their "real self" as behaving a certain way, for instance stimming on colored Christmas lights, they might start stimming on colored Christmas lights again in an attempt to act like their "real self". But since it is out of context, it often becomes just another act, and things get convoluted.

The following is something I wrote to someone who was dealing with this, that may apply to others as well. I have modified it a bit for increased clarity.

First off, because many autistic people take things literally, a search for a literal "old self" will not work. It leads into a really convoluted and inevitably dead-ending mental maze that is probably best avoided (it's exitable, but it's not exactly fun or useful to spend time in any more than a pretence is). You have changed over time, and any person that you were before you started pretending to be NT has gotten older.

The good thing, though, is that (since it's actually impossible), you've never actually gone away. Most likely, you've spent a lot of energy and most of your thought in dealing with the demands of looking normal. There was a person doing that, even if others influenced your actions — you.

What would probably help in a situation like this is to get away from the demands of that pretence, and to stop the pretence whenever you see it happening. Not beat yourself up about it or something, just decide it's not something you want to be doing. Do something else, instead — something that doesn't require a social facade. Start noticing how you feel. Start paying attention to how you react to things, what you seem to like, and what you seem to dislike. These are signals that, if you're pretending to be someone else, you've probably had a lot of practice at ignoring, so this takes time. Start noticing reactions in your body and stuff. You may not know what they mean at first, but after awhile (sometimes a long while) you should be able to pick out patterns. This can be scary, and *none* of this is a remotely trivial or easy undertaking, but it can also be worthwhile.

If you have responsibilities that *require* a facade, this can be harder to do. Make time when you don't have these responsibilities, and schedule a lot of time doing *nothing* at first. (Autistic people often need that time to even process information, so you may find that doing nothing a good deal of the time helps you think better and rely less on facades.) Or find something repetitive but non-facade-requiring to do, if sitting around isn't your thing. The critical thing there is to do something *apart* from the responsibilities that require an NT-facade, and start noticing the difference between the facade and the rest of the time.

You'll probably make mistakes, and you'll probably change over time, and you may find all of this scary. You may decide that an idea you had about yourself doesn't work anymore. You could have been mistaken, or you could have changed. Either one of

those is pretty standard for being a person.

So it's actually not that you have to look for an old self, and dig into your past to find one -- what you likely need to do is stop moving so fast to keep up a pretence, that you can't see who you are *right now*. Because one thing that's guaranteed, even if I haven't managed to outline a good method of seeing it (I don't know you), and even if whichever method there is isn't a particularly easy one, is that you're there.

That may not be the exact route to dealing with the sense that you've lost yourself, but the bottom line is still that you *have to* exist or there would be nobody looking for you.

### **Loss of alone time or breaks**

Some autistic people, especially but not limited to those who try not to look autistic in public, need a lot of time alone in order to do what comes naturally — stimming, talking to themselves, and other such things. A lot of us also need breaks from the overload of being around people or functioning in environments designed for non-autistic people. We need these things the way people need sleep in order to function.

We might lose the opportunity for these breaks for a number of reasons. Some so-called therapies for autism or other things emphasize not allowing people to take breaks, or not allowing people to "isolate" or "withdraw". Sometimes it is a change from a school or work environment in which we can get away with running off to the bathroom frequently, to one in which we cannot. Sometimes it is moving in with a roommate or getting into some other situation that requires more frequent contact with people or other overloading situations.

If a person doesn't get enough sleep, they start falling asleep sitting up. If a person does not get enough breaks, the breaks start trying to happen whether the person is alone or not. As the person gets more overloaded, they may do the things that they would normally only do alone, or they may shut down in ways that give them a "break" without having to physically leave the room. All of these things can lead to a person looking "more autistic".

### **Natural part of autistic development**

For autistic people, it is *normal* to develop in an order that perplexes anyone who is used to the way non-autistic people develop. It may be that some of the normal patterns of development for autism involve things that look like loss of skills at different stages of life, or fluctuation in abilities of various kinds. This may not require any external or internal agent interfering; it may just be the way things are for some people. Just as non-autistic people go through specific developmental phases, there may be a whole different trajectory for some autistic people, that looks like it goes backwards in spots *only in comparison to the non-autistic norm*. It is hard to say, though, whether anyone will ever learn either way.

### **Overprotection**

When other people are controlling your life, making all of your decisions for you, and keeping you "safe" from any possible failure, it's possible to either lose or fail to develop skills for doing various things yourself.

I have seen this used as an argument against services for autistic people, the argument being that they coddle us and make us dependent. I do not believe this to be the case — too little help can be a very negative thing as well. The distinction I made when I was applying for services was this: "I want to be helped, but not helped into a corner." What constitutes help and what constitutes being helped into a corner can differ from person to person and change over time, but when help starts to turn into control, that's a warning sign. When a person is never allowed to fail or take risks — both of which can be essential for learning — that is another warning sign.

Violence is a not-uncommon reaction to the frustration of being smothered by the "care" of others, yet it is often labeled regression and summarily dismissed as having no knowable cause.

## People Nearby

[Added 13 May, 2005]

Autistic people can be sensitive in various ways to the presence of people:

- Becoming more able to do certain things when people are present.
- Becoming less able to do certain things when people are present.
- Becoming more able to do certain things when *certain specific kinds of* people are present.
- Becoming less able to do certain things when *certain specific kinds of* people are present.

Changes in the amount or kind of people around can mean changes in abilities. There are some kinds of people where, immediately upon meeting them, I am incapable of using language. There are other kinds of people who seem to make language easier. This is true even if they are strangers.

## Physical health

This goes along with basic physical needs. Sick people don't function all that well either, and with a more limited amount of energy, you're going to need to use more autistic-looking strategies for dealing with the world, because you won't have the energy to use more complex strategies. You also may not be able to tolerate as much input before shutdown occurs. I had an untreated gallbladder problem that probably lasted for several years, and in the last month before my surgery (by which point my gallbladder had long since produced two large stones and shut off) I could barely tolerate any stimuli before becoming incapable of communication or responsiveness. Many things that cause physical pain, even if you don't consciously *feel* the pain, can do this.

If you have any chronic health or chronic pain condition, expect it to have a long-term impact. When you've got less energy available to spend on thinking, perceiving, and reacting, then often the things you're least skilled at are likely to become even more difficult, sometimes spectacularly so.

## Religion

This topic has been so thoroughly abused and exploited I am wary of mentioning it. But for the sake of completeness, people who are dealing or grappling intensely with issues of religion, faith, or conversion, whether positive or negative in nature, may show more, fewer, or simply *different* autistic or autistic-like traits than they had in the past. This is not necessarily a good thing, and it is not necessarily a bad thing. If you need help dealing with these issues and are part of a religious community in which you feel comfortable talking to someone, you may want to talk to that person.



You could also talk to your deity, if you believe in one. Be cautious about discussing these issues publicly, as there *are* unscrupulous or misguided people both inside and outside the autism community, who look harmless or inviting but could play to your ego or attempt to abuse, confuse, or exploit you in the name of religion or spirituality. Likewise, there are many books out there that are little more than compelling garbage.

## Self-consciousness

Some people, when they realize they have a trait, become very self-conscious to the point where somehow it enhances the trait in question. Some people may also perseverate on autistic traits, and sometimes focusing on them makes them more pronounced. (In other people, focusing on them and self-consciousness cause them to avoid them, but it can work both ways.)

## Self-injury

This, like catatonia, is more a description of a kind of behavior than the cause of behavior, but some people refer to increased self-injury when they talk about looking more autistic.

I think most self-injury is not autism, although it can be related to aspects of being autistic (such as sensory differences), living as an autistic (such as the abuse many of us are subjected to), or things that often go along with being autistic (such as [Tourette's syndrome](#), compulsions like scab-picking or [trichotillomania](#), and tics). Some autistic people also self-injure when they are trying to accomplish a difficult task. Lucy Blackman talks about biting her hand when she wanted to come up with words. Some autistic people also do things that technically are self-injurious but that don't *feel* self-injurious. You might like the texture in your mouth of biting your skin, but not feel the pain on your skin. Self-injury can be a reaction to stress, or to any of the things that cause self-injury in non-autistic people. There is a myth going around that autistic people who self-injure do it "just because they're autistic", but many autistic people report self-injuring for all the same reasons everyone else does.

## Support Level Changing

[Added 13 May, 2005]

When I have gotten good, reliable support to do basic things, then I have more energy free to do other things. I start being able to, for instance, retrieve water more often, use the bathroom more often, navigate the house more readily, and even recently clean up a little. When staff are not there, however, I have to do more things, which in the end means being able to do none of them.

Many autistic people report this, and it can be a barrier to services. I have known autistic people who can be very competent at many things as long as they have the services in place. Then once that happens, the people providing the services say "You're too competent to need the services!" The autistic person then ends up in a situation where their services are cut off and spend all day sitting in one spot rocking back and forth, with all the problems that implies for survival and cleanliness.

Some autistic people also report that, upon receiving support services, they become *less* capable of some things they were previously able to do. This can be because of the presence of [people](#) so often in their lives, their bodies finally allowing [burnout](#) to happen now that it's possible to survive

without doing certain things, the dynamic described in the [overprotection](#) section, or many other things.

## "Therapies"

Some "therapies" for autism can cause a loss of skills. A woman at the organization CIBRA describes how her son showed a good deal of interest in books as whole objects before his behavioral program started. Then, they started using flashcards with out-of-context words in the behavior program. Instead of being interested in books, he saw each single page as a "goal", as if he now saw books as flashcards. (A link to the website containing this story is provided at the bottom of this page.) The behavior program also caused him to lose his toilet-training by making him terrified of toilets, and I have heard reports from another parent who said the same thing about her son. It is fairly common, if underreported, for intensive behavior programs to cause people to lose skills.

Some "therapies" might force an autistic person to do something that uses up too much of her energy reserve to do anything else, or may overload an autistic person. This can include some alternative therapies like Reiki: I am not the only autistic person who has been overloaded to the point of catatonia when it was applied to me.

Many restrictive diets can cause a person to lose essential nutrients, essentially causing starvation. Some doctors promoting those diets will refer to any resulting problems as withdrawal, but it is quite often the body's natural reaction to deprivation of a nutrient (so is the initial feeling of well-being, which is also experienced by anorexics). Many autistic people have legitimate food allergies or intolerances, but *many, many* quack doctors will administer faulty tests to *convince* you you have allergies or intolerances that you do *not* have. It is important not to trust something just because it is a blood test or a urine test — there are *many* tests out there that have been proven to have no validity at all. Keep in mind that the doctor may sincerely believe in the tests or the diet — not all quacks are deliberate frauds. But if you have suspicions, it's best to check them out. The results of this kind of deprivation can cause the same problems that not eating enough can cause, and can cause a person to have less energy reserve.

## On Deliberateness

A lot of people believe that everything about autism is purely pathological and that therefore any common autistic strategy for dealing with the world is also pathological, and should be replaced by something closer to how non-autistic people do things. In reality, many of the strategies autistic people use for dealing with the world *work for us*, despite the fact that they would not necessarily work for non-autistic people. Likewise, non-autistic people's strategies do not always work for us. Different brains require different solutions.

Unfortunately, there are people who believe that because everything about autism is (to them) pathological, then deliberately adopting autistic-style strategies that were not used previously is also pathological. If an autistic person *purposely* decides to start doing things he has not done before — or has not done in years — then this could be seen as a sign that something is very wrong rather than a sign that he is learning to do things in the way that is right for him. Motives will be attributed that do not apply, including being "attention-seeking" (which, I should point out, is a term that

technically applies to anyone who initiates a social interaction) or having no respect for people who have no choice (in others' eyes) but to do things the way he is doing them.

This attitude is wrong. The words "deliberate" and "volitional" are not synonymous with the words "pathological", "attention-seeking", or "morally backward". Those words only apply to *some* of many other possible volitional acts. Many other people deliberately do things that they think will make their lives better, and if this does not work, will change what they are doing. The idea of *deliberately* doing some things in an autistic way is considered by some to be something on the order of slightly disgusting, a sign of a morbid fascination or manipulation. Suffice to say that this is not the way *I* am using the word "deliberate" in this document, and that I wish more autistic people could learn certain ways of dealing with the world from other autistic people.

## On Regression

I don't like the word regression, which is the most common word used when an autistic person starts losing skills or appearing more outwardly autistic. I also don't like the terms setbacks and backsliding in this context. This is not because it isn't politically correct, but because it's both inaccurate and loaded with the potential for erroneous and damaging conclusions.

One reason I don't like these words is because they essentially mean growing backwards. I do not believe it is possible for a person to grow backwards. I have lost skills during two major periods of my life so far. I have never grown backwards. In some people, also, looking more stereotypically autistic can be a positive sign — a sign that they are no longer faking things, for example, and that they are learning how to do new things *their* way, a way that works better for them. This is not true for everyone, but I don't think the concept of growing backwards applies.

Another reason is the way people *treat* a person when they believe that person has grown backwards. There can be a tendency to view a person almost as if they have died, and been replaced by a new person. People say "I want the old you back," meaning they want their fantasy of what you would have been like if you had not changed in certain ways. This can also happen to people who have changed after a traumatic event, or after brain damage.

From the point of view of a person who has lost skills, this put a tremendous amount of pressure on me. Every time I did something that seemed to show a gaining of approved skills, it got called progress, and every time I even *took a break*, much less lost those skills again, it got called setbacks, backsliding, or regression. I started reacting with violence every time I heard one of those words, which I doubt is the effect people around me were looking for. It felt like people didn't care about *who I was*, only *who I could have been*, and were determined to make me into their vision of who I could have been.

It was also not pleasant to be talked about *in front of me* as if I had died and someone else had taken my place. I was perfectly capable of hearing this, and the implications — that I was undesirable and inferior to people's fantasy of who I could have been — came through loud and clear. It made me feel like an unwanted person who had mysteriously taken the place of a real, desirable person, or like I was being haunted by other people's fantasy-ghost of who they wished I was. The person after I lost these skills, and while I was losing these skills, was and is *still undeniably me*. I was aware of many things people thought I was not aware of, and being regarded by many as irrevocably

damaged and inferior took its toll.

It is disrespectful to a person to expect them to measure up to the standards of a fantasy-ghost of who you wish them to be. It is possible to encourage a person to learn things and regain skills without making it sound like the person they are is inferior to the person they could have been. It can be especially important because *internalizing* the fantasy-ghost as a superior being can be a fast track to self-hatred and emotional or physical self-destruction. Respecting a person (or yourself) where that person is at, while possibly wanting to change some things, is much better for everyone involved than wishing that person were someone they are not. Losing skills can be scary. There's no reason to make it *more* scary by thinking of it as growing backwards or using emotionally provocative metaphors.

These words can cause problems for autistic people who have been faking normalcy for a long time. When people say "I want the old you back" or "You have regressed," it can sound to the person like "I liked the pretend-you better than the real you" or "To act like who you really are is to grow backwards, not forwards." This can devastate a person emotionally, and it can even shame them into expending an enormous amount of energy faking normalcy to the detriment of their health, their emotions, and their ability to deal with life. Since faking normalcy can kill through burnout or suicide, to refer to dropping a facade as regression or undesirable can have serious consequences. The same is true for people who use more stereotypically autistic ways of dealing with the world in order to make it easier to do other things, or people for whom learning to do something important to them can mean losing another skill somewhere else.

It is important to know that the growth of people is a complex process that cannot be reduced to a simple one-dimensional model of progress versus regression, growing backwards or forwards. Especially among autistic people, a person's normal developmental pattern can vary greatly. The consequences of many of the connotations of growing backwards are non-trivial both for people who have lost skills and for people who have dropped a facade or learned to utilize more useful autistic-style skills. Regression can be in the eye of the beholder, and personal growth or integrity is *not necessarily the same* as looking less autistic.

As for what terms *are* applicable, I think it's best to stick to straightforward descriptive terms that describe what seems to be *really happening* — loss of a skill, gaining of a new but unusual-looking skill, change in behavior, dropping of a facade (if you know that's what's happened), or anything else that seems like a true descriptor rather than something that draws too many conclusions. It's my belief that referring to becoming more autistic or to a lower functioning level draws as many false and broad conclusions as regression does.

## **An Analogy for Some Kinds of Autistic Skill Acquisition**

The following is *only an analogy*. The real world is much more complicated than this, and this is not true for all autistics.

Pretend there is a way of measuring doing a certain skill, so that there is a "resting performance level" in that skill and an "active performance level" in that skill. The scale is from 0 to 10.

9 or 10 is the way people are expected to perform in that skill.

Most NTs have a resting ability of 7 to 10 in a skill they have either learned or been born with.

Many autistics have a resting ability of 0 to 3.

In order for an NT to do that thing, it takes either very little effort or no effort. If their resting level in that skill is 10, then they don't even realize that they are *using* that skill.

In order for an autistic to do that thing, it takes considerably more effort. It takes the degree of effort that it takes NTs to do things that *they* usually have a resting ability of 0 to 3 in, such as multiplying large numbers in their head.

But when an autistic gets practice, they get used to pushing themselves.

They may push themselves so that in public they are functioning at between 7 and 10 in that skill at all times.

The NTs around them, taking for granted that 7 is the lower limit, don't even recognize that the person maybe had to climb all the way up from 0 to get to 7. They start taking for granted the autistic person's ability in that area, because it is within the limits of the only range of abilities they even *know*. The autistic person's effort gets unintentionally ignored, and NTs wonder what's going on when the autistic person gets exhausted and overloaded from doing "normal" things, or suddenly stops being able to do something they were "good at" before.

One example of a thing that NTs are usually at a 10 at is recognizing the objects in front of them. Unless they have had brain damage (at which point they're not technically NT anymore), they usually can easily and effortlessly perceive and differentiate between familiar objects and name them.

Some autistic people, in order to do that, have to do things like decide to look at something, see a garble of shapes, start differentiating individual shapes, focus in on one of the shapes, figure out that the shape is a Thing, figure out what the Thing is, and figure out what the Thing does. And that's all just to get to the bare minimum of what NTs do automatically, and it's leaving out things like differentiating one sense from another and doing this in a non-passive setting.

Doing that kind of thing all day with all your senses can be very tiring and overloading. That does not mean doing all the things NTs do to *function* all day, mind you, it just means understanding our surroundings. That's the *background* that a lot of autistic people have to work up to to then do the "ordinary" things like go to school, obey teachers, do schoolwork, housework, and stuff.

Some autistic people can get extraordinarily good at holding this together to the point where it becomes pseudo-automatic (doesn't require conscious effort, but takes a huge energy drain), or can devise ways of dealing with the world that don't involve having to perceive all of it all the time, but there are usually things going on that an autistic person is doing consciously that are a lot more basic than what you're used to thinking about. It's not necessarily always in the area of sensory perception; that's just one of many things that can be like that for us.

It doesn't often get recognized that even if an autistic person gets up to a metaphorical level of 7 to 10 in a skill, and performs that skill in that manner on a regular basis, in all likelihood they are still performing all of the complex maneuvering consciously. We are less likely than NTs to just get used to things, and even when it becomes pseudo-automatic the drain on our resources does not

necessarily go away.

The natural inclination of many NTs when they see an autistic person at a 7 to 10 in that skill is to believe that that skill has been "mastered" and is now fully automatic, requiring very little effort. They then push the autistic person to pile more skills on top of that skill, into a really big stack. The problem is that the more skills get added that the person then has to monitor and deal with, the more likely that the lower-level skills will falter and bring the whole metaphorical "house of cards" down. That can look like overload, shutdown, or meltdown when that happens.

When it happens for a long time and some of the skills do not get built back up again, then it often gets called "regression", which is not a word I'm fond of. I suspect that's *one* reason that autistic people sometimes shut down on skills we've supposedly mastered a long time ago when learning new things. Skill mastery simply doesn't work the same for us.

## **You May Never Know**

You may never know why your autistic tendencies suddenly or gradually seem to be increasing.

I certainly will probably never know for certain what combination of factors caused these things in me. All but three or four of the things I have listed apply to my life in some way, and I don't know in what manner they have combined. Any of these things could cause me to lose skills, to use autistic ways of dealing with the world in preference to non-autistic ones, to be less able to hold up any semblance of non-autistic behavior, to lack the energy to hold up skills that took a lot of energy in the first place, or to find myself acting or being perceived as more obviously autistic for any number of other reasons. Taken together, there is no possible way I or anyone else can sort out which thing caused which other, although I can make guesses. The only thing I know is that my development has been anything but predictable, and *some* of my autistic traits stand out much more prominently in adulthood than they did in most of childhood (with a long intermediate phase in adolescence where they fluctuated into heavier prominence), despite having been clearly born autistic.

This uncertainty may well be the reality for a number of autistic people who read this. Autistic people are subjected to many common experiences, and have many common things ranging from epilepsy to self-injury that happen in a lot of us. We are more likely than non-autistic people to be abused at some point in our lives, and to have to overwork ourselves beyond our natural capacities in order to keep a bare minimum of survival in the societies we currently live in. Given so many possible factors, it may be possible to isolate a few that are more likely than others, but most likely you'll be left wondering in many ways. I hope that this has at least provided places to look for more information.