

The Great Misunderstanding

Asperger adults describe their experience of sensory overload



Compiled and illustrated by
Tania Melnychuk

First Edition
Version 2

The Great Misunderstanding

Asperger adults describe their experience of sensory overload

First Edition, Version 2

2010

This book may be freely copied and distributed,
but not sold.

CONTENTS

Introduction	1
About the interviews	3
About the illustrations	3
Interviews: Asperger adults describe their experience of sensory overload	4

*With thanks to my family, friends and colleagues,
for trying to understand.*

Tania Melnychuk

INTRODUCTION

Why it is important to understand sensory overload

I was diagnosed with Asperger Syndrome at the age of 43. Between 2008 and mid-2010, I frequently experienced the sensory overload typical to autism, and the vicious cycle of sensory overload and anxiety.¹

Before this time, I had not even heard of sensory overload, and I could not account for the extreme outbursts which I had experienced occasionally the years before.

As I gained more knowledge about my Asperger brain, I learned how my neurophysiology — that of my frontal cortex, amygdala and basal ganglia — differ from those of a neurotypical person. During an autistic meltdown (the term which describes my hitherto inexplicable outbursts) all of these parts of the brain play a role.

To understand sensory overload, which is often the pre-condition for a meltdown, we first need to understand what is happening in the basal ganglia. The process which takes place in this part of the brain has been well documented by scientists and they can explain it better than I could do here. All these details, however, remain of mere academic interest unless one appreciates how severely sensory overload affects many people with Asperger Syndrome, and the degree to which it impacts their mental and physical health and their relationships, particularly if overload occurs regularly. Repeated and prolonged overload can result in constant anxiety, turning eventually into depression, physical deterioration and an inability to concentrate, to communicate and to maintain normal eating and sleeping patterns, making the sufferer vulnerable to illness. The result of this suffering may even be suicide.

My own experience of sensory overload

My own experience of sensory overload should not be taken as the only manner in which this phenomenon manifests itself. I am only one aspie. My overload is brought on primarily by particular types of sound and also by sharp contrasts in light, especially when simultaneously surrounded by movement, such as in an open-plan office. It is exacerbated by working for too long without a break, by not eating regularly and in particular by misunderstandings which result from my increasing inability to communicate effectively or to control my anxiety as a result of such misunderstandings.

At worst, this can result in what appears to be an aggressive lashing out. I become either unable to control anger, or more often I experience an extreme fear of being misunderstood and of damage to the relationship. I may remove all my clothes as my skin begins to feel scratchy and my body becomes very hot. I scream. My limbs and body begin to contort and I unwittingly push myself into a corner as my body craves the deep joint pressure which can help to restore my senses to a normal equilibrium. In seeking to combat the intense scratching, itching feeling deep below my scalp, and possibly also my racing thoughts, I am often tempted to hit my head against the wall — an urge which I either contain or deflect into some other form of self-injury.

In the end, I sit huddled in a corner, rocking to and fro or shaking my arm rapidly as my mind races through the same looping thoughts, unable to resolve the problem. And then comes the exhaustion.

Learning to cope with sensory overload

I have now come to recognise the early signs of overload, and wherever possible, I remove myself to a situation where I can recover. My family, my neighbour and my colleagues understand this better now, and if they know I am in overload, they are usually aware of what I need. In such cases, the overload is still extremely unpleasant; it feels as though a substance which does not belong there is being diffused into my brain, and I cannot fight it. However, there is no anxiety. When the overload is full-blown, I become mute. I may struggle even to send a single-word SMS from my cell phone. I try to find somewhere (or someone) who can provide my body with pressure; I lie down and cover my eyes and ears with my hands. There is, unfortunately, no good way of significantly speeding up recovery. Sensory overload is very tiring, and when it is over — if I am fortunate enough to be in a position to do so — I may fall asleep.

¹ Specialists in sensory processing distinguish between sensory overload and the final stage of sensory shutdown. This distinction is not made in this document, as many people who experience these things are not aware of both terms and of the distinction between them. Some of the experiences described in this document may thus more correctly fall under the category of shutdown.

Sensory overload looks different in different people

As has been my own experience, where overload occurs while social or work demands are being made of the person who experience it, the result for many people takes the form of an obvious meltdown which is almost invariably seen as extremely rude. However, this kind of outburst is not the case with everyone who experiences overload. Some people, in order to prevent themselves from doing anything which might appear rude, suppress their defensive anxiety, trying to appear normal while their ability to communicate rapidly deteriorates. Their apparently surly appearance belies the frightening, overwhelming experience which is taking place inside. As Pensieve² explained once, this can be even more harmful to the person experiencing the overload, as it can lead to a racing heart rate, dizziness and nausea, accompanied by the same exhaustion, vulnerability to misinterpreting other people's actions, fear, tactile defensiveness, shaking and temporary mutism as is often experienced by those who have more explosive meltdowns. Relationships may suffer equally, as those who live and work with such a person have no idea what is really going on, and may for many years continue to make demands on such a person's attention and time far beyond his or her ability to bear.

The purpose of this book

My purpose with this book is to assist neurotypical³ friends, family members and colleagues of adults with Asperger Syndrome, as well as doctors and therapists, to understand what sensory overload feels like, so that they can be in a position to assist in preventing it or at least dealing with it when it does occur — just as some of my friends, my neighbour, my colleagues and my mother are now able to assist me.

To this end, rather than elaborating further on my own experiences, I asked a number of adults with Asperger Syndrome to relate what they feel. The spectrum of symptoms, social problems and coping strategies may provide a clue to what could be happening to others who have not yet had the opportunity, courage or words to articulate their own experiences.

Many of the respondents have never been able to articulate what they feel in conversation with the neurotypical people they see every day. Aspies are notoriously difficult to 'read', and their difficulty in labeling feelings is one of the well-documented handicaps common to many.

I regard my autism as a blessing. Aspies have much to offer the neurotypical world by virtue of their special skills and perspective on the world, and often also their great compassion. But the rose that is autism also has thorns, and sensory overload is one of them. Aspies need help in ensuring that sensory overload does not cause harm to them or to the people in their lives.

I hope that this compilation of experiences will open up the understanding that is needed to make that possible.

² A pseudonym used by one of the respondents who took part in the interview.

³ "Normal", not having Asperger Syndrome.

ABOUT THE INTERVIEWS

For many aspies, it is easier to communicate by writing or typing than by speaking. None of the interviews were conducted person-to-person. I provided a questionnaire, and those who volunteered to participate chose which questions they felt they could answer, typing the replies. One or two respondents reformulated the questions slightly.

Here and there I edited a response, usually to remove certain formatting or chatty details not directly pertinent to the topic. Where edits involved cutting text, I usually indicated this below the pseudonym of the respondent.

In most cases, however, I left the responses as-is, including the original spelling and punctuation.

The questions I asked were:

- 1. What 3 things that lead to sensory overload for you?**
- 2. What does sensory overload feel like?**
- 3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?**
- 4. What 3 things do you wish people would understand about you when you experience sensory overload?**
- 5. What 3 things do you wish people would do for you when you experience sensory overload?**
- 6. What 3 things help you to prevent sensory overload?**
- 7. What 3 things help you to recover from sensory overload?**

ABOUT THE ILLUSTRATIONS

The illustrations are my own (hastily painted) pictures. They are anatomically imperfect, and as an aspie, that bothers me a lot, but logic tells me to compromise by including them anyway, as I felt that this book does need *something* more than mere text.

I have yet to find a better way to visually describe sensory overload, and I am not sure that these pictures accurately tell even what I feel. If, however, I have at least managed to convey a sense of being overwhelmed by one's surroundings, this is perhaps enough for now. Perhaps other aspies can share their own illustrations in a future edition.

INTERVIEWS: ASPERGER ADULTS SHARE THEIR EXPERIENCE OF SENSORY OVERLOAD

WAVEFREK58

Too many questions. That is actually a form of overload for me. I am compelled to answer as accurately as possible which takes effort and concentration. The result is that I default to sarcasm as a way of deflecting the task.

In general, noise and multiple sources of input (phone ringing, too many people talking all at once) overload me and I just stop processing things. Sort of slam the door on further input.

Paradoxically, if the noise is related to the task I am focused on at the moment, I am quite tolerant of it.

DALTON_MAN321

Noise and it used to be people requesting/demanding me to do things on the spot when I'm not prepared. And when that happens it goes a little like this:

Dalton's mind wrote:

It is now safe to turn off your body.

MISSLOTTIE

This reply has been slightly edited

um, yes- too many q's.. because its visual/cognitive overload, essentially... so i expect most people will answer randomly... also- your q's are too NT- we think in a more meandering way... sorry- i hope that doesnt appear rude. anyway...

i suffer from noise most of all- just awfully- bass music just SLAYS me. its pretty aful. its hard to describe- upsetting, frightening, confusing- then i tired and shut down.

visual overload is next- seething stuff- like crowds of people viewed from the top deck of a bus- just feels the same- unsettling, confusing- i close my eyes. i can also get meltdowns from both..

conversly, however, i LOVE music, and im stoked to be off to the opera next week for tannhauser- wagner's music gives me a really good bass dose. i have synesthesia, so it crosses into that.

anyway- its like a menatl hypothermia- or your laptop battery closing down; the non essentials close down, but the core is ok, still blinking away- just not enough power for the peripherals to work. you jst...close...down.. oh! like the tin man in the wiz of oz.

id also suggest using the wp google custom search option- top right- for this- it comes up ALL the tie, and you'll find loads of links and stuff.

BECKY13

1. Surprises, parallel input on multiple channels, noise.
2. Overwhelming need to remove myself from situation, which may not be possible (which often leads to crying).

3. I no longer have the ability to put the social veneer (fluff) on stuff, so I become "rude", "impatient", feel cross or upset, shout or cry, or run away.
4. Acceptance, I do not require admonishing beyond what I will do to myself.
5. Leave me alone for 5 mins, but COME BACK!! Difficult when I've shouted at someone, they don't usually want to come back for an anticipated second helping. Would be one of my Blind Date questions, "erm number 3, we are out for dinner and are half way through our meal when I start crying for no reason at all and am just staring at my hands, what do you do...?"
6. Preparation, serial input on one channel (pref visual not verbal), sunglasses.
7. Lying on my bed with the door shut works surprisingly well, otherwise some sort of time out. I don't have 3 things, it's sort of a process that recovers itself.

ZWEISAMKEIT

just like the others, too many questions, and my mind doesn't know where to start.

I'll rewrite them and post like its a quiz..

1. What 3 things that lead to sensory overload for you?

certain fabrics that are itchy, loud sudden noises or loud ring tones, or loud music that i do not find soothing, people touching me/hugging me/in my space

2. What does sensory overload feel like?

feels like a panic starting... i can feel it welling up inside of me.. my thoughts begin to race... i feel i have to get away to a quiet place.. it can manifest as me being angry, crying, or sometimes even selectively mute.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

It makes my sensory overload multiply.... if i am having an overload/meltdown, i want to be left alone... if i get asked questions, its more likely that i will lash out at someone.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

1. I need time to recover from it.... leave me alone in peace and i will be fine
2. dont act like it is a big deal... if i am over a meltdown, dont bring it up, i may start to feel overloaded again.
3. it isnt really anyone's fault. dont give me a guilt trip or pity party because it happened.... and DONT give me a hug.

5. What 3 things do you wish people would do for you when you experience sensory overload?

1. Leave me alone
2. Ignore the fact that i'm having a melt down.
3. dont touch me

6. What 3 things help you to prevent sensory overload?

1. Being organized and having a routine
2. quiet time prevents my sensory overload
3. being able to wear comfortable clothes makes me less prone to sensory overload....

If i can wear my jacket, then i feel secure.... its like a security blanket. If i am feeling extra shy, i can zip it up and pull the hood close to my neck and i feel calm.... Weird, huh?

7. What 3 things help you to recover from sensory overload?

1. Quiet time/maybe a nap
2. focusing on my phone, playing something like sudoku or chess
3. my jacket.... makes me feel secure.....so soft fabrics...

THEBICYCLINGUITARIST**1. What 3 things that lead to sensory overload for you?**

Surprises, crowds, strong input (bright lights, loud sounds)

2. What does sensory overload feel like?

I ask others to imagine they are skinned alive in a world that rains salt, with blinding strobe lights, howling sirens and that sound where people scratch a chalkboard. The longer it lasts, the more dazed I become until I am practically comatose.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

I realize they can't understand why I can't handle it, but it just adds to the severity of the attack. For example I sometimes go shopping at a busy crowded Walmart with a friend who doesn't stick to a plan, puts stuff back on the shelf the other side of the store when she sees something she wants more, and takes WAY too long to shop. I can handle it for ten or twenty minutes, but I become increasingly dazed after that faster and faster until I have to go outside. Even there, there is still too much going on for me to recover completely until I get home. She gets mad at me for "ruining" her shopping experience.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

That it is happening, it is not my fault, and I'm sorry if I'm letting them down.

5. What 3 things do you wish people would do for you when you experience sensory overload?

Help me get to a quiet safe place to recover, not try to keep me in the place where this is happening, back off.

6. What 3 things help you to prevent sensory overload?

Avoid crowded, busy, noisy places. If I have to go there, earplugs help a little. Planning ahead so I'm not surprised, and sticking to an agreed plan or schedule would help too so I'd know when it will be over.

7. What 3 things help you to recover from sensory overload?

Peace and quiet, lying down, maybe browsing WrongPlanet forums lol.

KAKASHIYAY

To answer all the questions with one response:

Imagine you're at the heart of the Las Vegas strip. It's 115 degrees out. The noises are amplified so they all hurt your ears yet you can still make out each individual noise and source. Each light is many times brighter than you are comfortable with, and each time a single light flashes or blinks, you notice it. There are hundreds of people pressing against you and talking to you. Your body is being pulled and tugged and squeezed and brushed by unseen hands. Your mouth is filled with the most repulsive texture you can imagine. You can smell every person in a 20' radius. All of these things are happening at once, and someone comes up and wants to talk to you about something really important. You know you need to listen to them, but with everything going on in the background, it's almost impossible.

How would that feel? What would you need to do to feel better? How would you like to be treated when that's happening?

KC8UFV

1. What 3 things that lead to sensory overload for you?

Too many things happening at once, however if something triggers my adrenal gland, sensory overload generally doesn't happen until after that gland switches back off. Instead, my mind jumps into hyperdrive, processing critical information, and throwing out all social information.

2. What does sensory overload feel like?

general headache, overwhelming urge to retreat. Panic. If lots of voices are involved with the overload, a brief, loud outburst may be triggered.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

It causes me to give short, quick responses, and become extremely forgetful. Frequently, I will completely forget what happened when overloaded, as if I am there in body only.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

I need time to recover.

5. What 3 things do you wish people would do for you when you experience sensory overload?

LEAVE ME ALONE

BE QUIET

LEAVE ME ALONE

6. What 3 things help you to prevent sensory overload?

expectations of what is going to happen

itemized lists, and don't just tell me, as that takes more overhead to process.

7. What 3 things help you to recover from sensory overload?

Quite, isolation, time

CORROONB

This is very difficult to articulate in a way that will make the experience comprehensible .

1. What 3 things that lead to sensory overload for you?

Many different things but mostly loud noises like car horns, loud music, lots of people talking in a large crowd.

2. What does sensory overload feel like?

It feels like being suffocated by information and leads to very panicky and anxious feelings. I feel everyone is looking at me.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

It makes me feel very stressed and defensive. Embarrassed that I come across as stupid or retarded.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

I'm not going crazy. It's nothing to do with them so they shouldn't feel hurt if I have to withdraw.

5. What 3 things do you wish people would do for you when you experience sensory overload?

Leave me alone. Let me go somewhere quiet to cool down. Not hold the withdrawal against me.

6. What 3 things help you to prevent sensory overload?

Getting adequate sleep. Nothing else appears to do any good. Avoiding places at certain times of the day. If I can't get out of the situation, like a noisy bus for example, I tend to space out, dissociate.



7. What 3 things help you to recover from sensory overload?

Breathing exercises to reduce the physical anxiety. Going somewhere quiet.

MATT

1. What 3 things that lead to sensory overload for you?

Unusual sensory input(sticky things like sap or soap or syrup, static cling, oil on my skin, fabrics whose textures are different depending on how you touch them)

Intense sensory input(bright lights, high-pitched noises, deep bass, perfumes, being required to use multiple senses at once, combinations of textures)

Unexpected sensory input(touching me, especially unexpectedly, being exposed to sensory input suddenly and without having time to prepare)

2. What does sensory overload feel like?

It feels like an overwhelming feeling that something is wrong and I need to stop it. If I can't stop it, it can cause a panic attack.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

I'm amazed that they don't understand and don't feel the same things. I can't focus when it's happening. Being asked to communicate in those situations adds more stress and makes me freak out. It's like being asked to simultaneously hold conversations with three different people who speak three different languages.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

I am seriously experiencing it. I am not exaggerating!

It has nothing to do with you, and I am not trying to bother you.

If the sensory input is stopped and if I am left alone for a while I will calm down.

5. What 3 things do you wish people would do for you when you experience sensory overload?

Make it stop.

Don't try to comfort me and especially don't try to touch me.

Leave me alone until I calm down.

6. What 3 things help you to prevent sensory overload?

Letting me avoid it or helping me avoid it

If it's unavoidable, preparation, far in advance, so I can be aware that it's going to happen. It is still likely to happen, but if I can be aware of it and aware of how long it is likely to last, I can stay calmer.

Minimize the time that I will be exposed to it.

7. What 3 things help you to recover from sensory overload?

Getting me away from whatever is overstimulating

Getting me to a place where there is little sensory activity. A calm, quiet place, with as little activity as possible, with no people, where it's dark or at least shaded, and doesn't have any strong smells(not even smells that other people may find pleasing).

Time alone not having to speak. Having a conversation requires sensory activity and does not help. If I initiate it, holding my hand may be okay.

HIGFAM2

Wow! that's a lot of questions! Here goes...

1. What 3 things that lead to sensory overload for you?

a. Loud sudden noises or too many noises for me to process, Bright lights (flashing or not), people touching me/hugging me/in my space

2. What does sensory overload feel like?

a. It feels like a panic attack starting... I can feel it welling up inside of me.. my heart starts to beat too fast... I start sweating... my thoughts begin to race... I sometimes lose my sight, or my hearing... I feel I have to get away to some place quiet... it can manifest as me being agitated, or I start to zone out, or my arm starts to twitch. If left unchecked I start to either faint or puke.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

a. It makes me so frustrated, on the verge of tears. I just want to be left alone... for the input to stop!... when asked questions or if not given space I will lash out at you... anything to just give me some breathing room.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

a. I need time to recover from it. Please let me go on a walk or leave me alone in my room. Give me some peace and I will be fine

b. Don't act like it is a big deal, don't fuss over me. Bringing up my meltdown will only cause another to start up.

c. It isn't really anyone's fault. I know that my behaviour is unexceptible, but I can not stop myself sometimes. Please don't try to guilt trip me or feel sorry for me, and DON'T give me a hug.

5. What 3 things do you wish people would do for you when you experience sensory overload?

a. Leave me alone, unless I ask for help!

b. If I ask you to help me get outside, JUST help me, this is not the time for 20 questions.

c. Do not try to hug or hold me

6. What 3 things help you to prevent sensory overload?

a. Being organized and having a strict routine

b. Time alone in my room, on a walk helps me recharge my batteries, preventing most sensory overloads

c. Being able to wear ear plugs or shades makes me less prone to sensory overload.

7. What 3 things help you to recover from sensory overload?

a. Quiet time, or a long walk.

b. Drawing cartoon characters, while listening to my music

c. Closing my eyes and focusing on controlling my breath

SCANNER**1. What 3 things that lead to sensory overload for you?**

Noise, smells, touching of things I don't expect. If the phone rings and a car drives by at the same time I yell and I usually get scared and start stimming. Certain smells, a lot of smells hurt my head. I am very sensitive to smells. Certain food gives me headaches too, like stuffing. I just can't eat it, I'm not sure what it is.

2. What does sensory overload feel like?

The end of the world sometimes. I panic, my heart beat speeds up. Especially with noise.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

Well I'm stressed and when people try to communicate with me I ignore them and focus on myself or act short with them.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

People think I'm not really feeling what I am.

They feel insulted as though I'm hurting them when they're being loud and it stresses me.

5. What 3 things do you wish people would do for you when you experience sensory overload?

Leave me alone.

Don't talk or try to comfort me.

Make the world quiet lol.

6. What 3 things help you to prevent sensory overload?

Staying out of situations that are noisy or smelly.

Knowing what's going to happen. If I know what's going to happen I may be able to control it better.

7. What 3 things help you to recover from sensory overload?

quiet

Mozart

LEEJOSEPHO

1. What 3 things that lead to sensory overload for you?

My wife, our cat (or TV) and a noisy washing machine all making sounds at once.

2. What does sensory overload feel like?

Claustrophobic mental confinement or entrapment.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

Feeling completely overwhelmed.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

Everything must stop so we can take things one-at-a-time;

Everything must stop so we can take things one-at-a-time;

Everything must stop so we can take things one-at-a-time.

5. What 3 things do you wish people would do for you when you experience sensory overload?

Stop everything so we can take things one-at-a-time;

Stop everything so we can take things one-at-a-time;

Yes, stop everything so we can take things one-at-a-time.

6. What 3 things help you to prevent sensory overload?

Doing just one thing at a time;

Avoiding people who expect me to even try to do more than one thing at a time;

Saying "Stop!" whenever anyone else begins doing more than one thing at a time around me.

7. What 3 things help you to recover from sensory overload?

The first, second and third hours of peace-and-quiet after everything else stops.

SCOOT\$5012**1. What 3 things that lead to sensory overload for you?**

1. Too many things going on around me at once
2. Too many things for me to do at once, especially if it something I'm not accustomed to doing
3. Certain noises

2. What does sensory overload feel like?

For me my brain starts to shut down. Thinking for me becomes a really slow and laborious process. Sensory information is ignored. Sights and sounds become really distant and incoherent. I get really fatigued and I feel like I want to go to sleep.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

I get really annoyed at people

4. What 3 things do you wish people would understand about you when you experience sensory overload?

1. I need some to time alone to recover
2. I need some to time alone to recover
3. I need some to time alone to recover

7. What 3 things help you to recover from sensory overload?

1. A quite place to lay down
2. A dark place to lay down

TITANGEEK

to many people talking at once.

PENSIEVE**1. What 3 things that lead to sensory overload for you?**

emotional stress, noise and flashing lights.

2. What does sensory overload feel like?

That fight or flight feeling, dizziness, being thrown underwater (sound can become muffled), dehydration (I've noticed when dehydrated I have the same physical symptoms as sensory overload or a meltdown).

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

I want to hit my head against something hard and scream.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

That it's a very debilitating, even if they can't experience it themselves. That I can't just snap out of it. That I have to get as far away from this stressful stimuli as possible.



5. What 3 things do you wish people would do for you when you experience sensory overload?

Not make jokes. It makes it worse. Take me away from the environment but not leave me on my own. Not be mad at me for having it afterwards.

6. What 3 things help you to prevent sensory overload?

Ear plugs, listening to music, having people with me.

7. What 3 things help you to recover from sensory overload?

stim toys (this can be a small object or a book, my phone apps or something I feel close to). An area away from people and low in stimuli. Actual stimming.

JAZZ1787

1. What 3 things that lead to sensory overload for you?

- too much noise (though clubs seem to be OK if im drinking Wink)
- people talking at me when im tired/stressed/have too much to think about (i just got home from work, i don't care what you did all day or what jobs you want me to do. I want to chill out for half an hour, then you can tell me)
- supermarkets, the lighting is terrible, the colours, the noise...

2. What does sensory overload feel like?

- sometimes my mind goes numb. I cant think, things agitate me and i feel a bit panicky
- sometimes i get really annoyed, just want to shut down and block everything out. If im home this involves finding a couch and laying down, sometimes closing my eyes, sometimes getting completely involved in a book or movie

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

- oh i usually snap (verbally) at them (no i don't care, im just sick of shopping and i want to go home!!)

4. What 3 things do you wish people would understand about you when you experience sensory overload?

- i need somewhere quiet and preferably dark. Or even a corner out of the walkway
- i will get back on topic in a few minutes when i calm down. Or i might not
- i'm not mad at you, im generally frustrated. I wont be snappy when you get me out of there

5. What 3 things do you wish people would do for you when you experience sensory overload?

- Stop. Talking. Please
- find me a quiet spot and maybe a drink. If there's no quiet spots find me a seat where i wont be bumped into by strangers
- give me a moment, im probably too stressed to care right then and there but i may be embarrassed later

6. What 3 things help you to prevent sensory overload?

- wearing my sunnies indoors
- going busy places at quiet times
- having a "timeout" when i get home, not launching straight into all the things you think i should be doing

7. What 3 things help you to recover from sensory overload?

- quiet, lack of motion
- cool drink, sometimes some headache pills as i often get a headache too
- dark, or sitting with my eyes closed

ZOKK

1. What 3 things that lead to sensory overload for you?

- Massive amounts of noise, light and motion, for long periods of time. Stuff like huge outdoor concerts, stadium sports, etc.

2. What does sensory overload feel like?

- Me liking my surroundings less and less as time goes on. Annoyance, boredom, tension.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

- Annoyance, distraction, disinterest.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

- I'm not mad at you, I'm just not in my happy place.

5. What 3 things do you wish people would do for you when you experience sensory overload?

- Shut up, go away, or both.

6. What 3 things help you to prevent sensory overload?

- Knowing my limits, going with a friend or family member.

7. What 3 things help you to recover from sensory overload?

- Quiet, solitude, company of close friends or family.

PENSIEVE

Motion is a good one. That affects me greatly. Also, the temperature, or even a thunderstorm. I'm very particular about how I want the weather to be.

CICELY**1. What 3 things that lead to sensory overload for you?**

- Noise, crowds, heat. Especially in combination.

2. What does sensory overload feel like?

- Panicky, nightmarish, nauseating, painful. Like a crashing computer. I can't process anything or focus. I just go back and forth between all the different stimuli. My instinct is to get out of the situation, but if I can't I'll shut down. I become withdrawn and slow to respond or react. I literally can't communicate beyond monosyllables and stock phrases. It's terrifying and it takes hours to completely recover.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

- It's frustrating. I get annoyed at other people for adding to my stress. If the person knows I have Asperger's and struggle with sensory overload, I feel like they should know better. But mostly I'm frustrated with myself for not being able to cope with things that don't bother other people, and for expecting other people to always know when I'm overstimulated and how to deal with it.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

- Sensory overload is a legitimate problem - it's not something I could get rid of by just trying harder. If I ignore people, brush them off, or leave the room abruptly, it's nothing personal; I just need to get out of an overstimulating environment. And thirdly, I need to be alone to recover from sensory overload.

5. What 3 things do you wish people would do for you when you experience sensory overload?

- Help me get out of the situation if possible. Don't try to have a conversation with me. Don't tell me to "just relax".

6. What 3 things help you to prevent sensory overload?

- Avoiding these types of situations in the first place. Leaving an overstimulating situation before it leads to full-blown sensory overload. Getting plenty of sleep and exercise.

7. What 3 things help you to recover from sensory overload?

- Solitude, quiet, a relaxing and unchallenging activity

WHO_AM_I**1. What 3 things that lead to sensory overload for you?**

It boils down to one thing: too many things coming in, my brain tries to process them all because it isn't capable of relegating any to the background, and I get overloaded.

People are the worst offenders. The three things I'd list would be sudden loud noises, too many different things coming into my senses at once, and people moving in unpredictable ways, which makes it difficult to navigate.

2. What does sensory overload feel like?

It varies. Sometimes it just feels like pain- a headache, sore muscles, sore ears and nausea. Other times parts of my functioning start to shut off- I feel disconnected from my surroundings, I start walking funny, my motor skills go to pieces, and my visual processing starts to break down. Sometimes, I don't feel anything more than mild dissociation, but I know I'll pay later with a migraine.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

Wait: it's possible to engage with people when overloaded?

4. What 3 things do you wish people would understand about you when you experience sensory overload?

1. Leave me alone. Any more input makes it worse. Even if you're just being nice and asking if I'm ok, the need to respond is more than my brain can handle.
2. If I manage to respond and say something like "Go away", please don't be too offended. What I really meant was "My brain is not working properly right now, and consequently I am unable to respond properly to you. I do apologise."
3. Leave. Me. Alone!

5. What 3 things do you wish people would do for you when you experience sensory overload?

1. Disappear.
2. Go away.
3. Leave me alone.

6. What 3 things help you to prevent sensory overload?

1. Avoiding excess stress.
2. Not too much sensory input.
3. Good general wellbeing.

7. What 3 things help you to recover from sensory overload?

1. Silence.
2. A dark room.
3. Time.

ANNIE OAKLEY

1. Light, heat, cold; and/or loud music and loud talking; and/or crowded places or gatherings where I don't know people. Ironically, when I used to have a great ADD job (law enforcement) those things enhanced my capabilities in a crisis situation that I was expected to handle.
2. I get headaches, stomach aches, the 'trots'; headaches, anger, frustration; headaches, the 'trots', need to escape and overall it feels like 3 or 4 very angry people screaming at me inches away from my face all at once.
3. Angry and want to lash out at them by yelling and leaving the area
4. Don't blame or get mad at me (I will do that to myself enough!), don't hug or pity me, be patient and understanding.
5. Let me recover alone, don't keep asking if I am ok, don't blame or make excuses for me or anyone else, drop it.
6. Always have sunglasses available, and gloves, etc., and avoid hot climates or rooms; stay out of noisy hair salons (I am a stylist), malls, etc.
7. Recovery for me is difficult. I have usually made a fool of myself and been very rude - so I stay away from people, and try to control the noise level in my life so that I don't have to recover.

PANGELINGUA**1. What 3 things that lead to sensory overload for you?**

Lots of people talking at the same time, loud music, or too many options, but the last is more cognitive overload - like too many options on a menu, having to try to make sense of all of them somehow. Also harsh lighting, perfume and air fresheners. Being tired means that all of these things effect me more, also.

2. What does sensory overload feel like?

Like wanting to escape, crawl out of my body. Sometimes it feels like millions of insects crawling around underneath my skin. Everything gets brighter and louder and more overwhelming. I stop being able to think or process information such as people talking to me.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

Usually it makes it a lot worse very quickly. Makes me feel that I have to retreat at all costs. It's very upsetting when you have lost the ability to speak or process information normally and people keep asking you why you're not talking to them.

4. What 3 things do you wish people would understand about you when you experience sensory overload? and 5. What 3 things do you wish people would do for you when you experience sensory overload?

I do not want to behave this way. I do not want to hurt your feelings or damage anything. However, I also don't have as much control of my actions as I normally do. This means that other people need to be the "grown ups" (even though I am an adult) and most of the things I want them to do are things I want them to NOT do.

Don't take my behavior personally (some people, if you are acting strange or having a breakdown, think it has something to do with them and they get angry, which is extremely frustrating and upsetting - so don't do that). Don't raise your voice or say sarcastic things to me. And please please please please do not touch me because then I will most likely hit you and then I will feel badly and you will get angry at me and be nasty about it and bring it up later in an attempt to make me feel guilty for things that I did when I was not in control of my behavior.

6. What 3 things help you to prevent sensory overload?

Getting enough rest and eating enough. Avoiding unnecessary overloading situations, especially if I am already tired. In unavoidable situations, ear plugs.

7. What 3 things help you to recover from sensory overload?

Sleep. More sleep. Special interests.

JOJOBEAN

I will answer you with poetry...I agree your questions are overwhelming

so here is my answer:

From Autistic View:2009

"Shrinking to a dot among dashes all around me. Sensory shutdown, my mind melts into a puddle on the floor and people are rushing through it. All I can see is a blur of color and energy as fall... into rush hour."

as you can see, crowds cause my worst sensory overload symptoms.

KISEKI

This reply has been slightly edited

1. What 3 things that lead to sensory overload for you?

Too many people, or me feeling closed in/trapped by them

Bright fluorescent lights

Heat/humidity

2. What does sensory overload feel like?

Very hard to explain. Basically I just feel like I will snap if I don't get back to my bedroom ASAP. By snap I mean start moaning and complaining to the point where I become childish. I feel really tired and just overwhelmed.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

Like I alluded to before, I just wanna yell at them.

5. What 3 things do you wish people would do for you when you experience sensory overload?

Be quiet, stop demanding ANYTHING of me, don't make me try to endure the heat/noise/bright lights any longer

6. What 3 things help you to prevent sensory overload?

I subconsciously started using headphones and an iPod when going anywhere. I've been doing this for probably 13 years now and I never knew before why I HAD to have my iPod on me at all times (not until I came to this site). I literally cannot go shopping without being plugged in. This really helps me stay in my own world and not be dragged into the noisy, bright, crowded one.

Sorry, that's only 1 thing.

7. What 3 things help you to recover from sensory overload?

Cool and quiet places where no people are around.

TOASTYTOAST**1. What 3 things that lead to sensory overload for you?**

visual stimuli, especially bright colors or lights (i can't stand grocery stores for this reason).

noise

crowds

2. What does sensory overload feel like?

i get disoriented, anxious and unhappy

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

first i get irritated and (admittedly) whiny and insist on leaving, and then i get very quiet and quit responding. i kind of shut down.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

there's only one thing, really: i need to remove myself from the situation (even if you don't think i do because you're not bothered by it!)

5. What 3 things do you wish people would do for you when you experience sensory overload?

take my problem seriously

try to be understanding/don't make fun of me

help me get out of my current environment

6. What 3 things help you to prevent sensory overload?

staying out of environments and situations that i know are going to be overwhelming, or limiting my exposure to them

having someone with me to help me not completely freak out

not being too tired/hungry/anxious/stressed/overwhelmed to begin with

7. What 3 things help you to recover from sensory overload?

making a quiet exit

finding a quiet space

being left alone to get back to normal

FIZ

I will try to answer these questions as best as I can:

What 3 things that lead to sensory overload for you?

There aren't as many things that do this to me anymore but my top 3 are as follows:

1. Big crowds - I tackle this by, for example, doing my Christmas shopping either online or on a weekday evening during October or November to avoid the December Christmas crowds. I use this as an example as I remember one year that I chose to shop on a Saturday in the middle of December for my gifts. It took me nearly 4 hours and, because I was so overwhelmed, I forgot some of them and one hour of that was spent crying in a toilet cubicle as I could not mentally take anymore. Never again.
2. Having more than one person trying to talk to me at once - why do people do this, just why???? How much attention do people really need???
3. Loud intermittent noises that show no sign of stopping and I end up stuck with them e.g. a loud alarm near my place of residence when I am trying to sleep.

What does sensory overload feel like?

I feel mentally overwhelmed and lack the ability to cope, even with things that I can normally cope with well. My response to this is that, if I cannot control it, I start crying or panicking. I can only relate in terms of a computer being so bombarded with information that it crashes or shuts down.

What effect does it have on you when people expect you to engage with them while you experience sensory overload?

Well, as I lose the ability to understand even the most basic of statements or questions almost completely, then having to interact with even one person causes me immense stress. The best way of describing this is that it is like, suddenly, that person is speaking to me in 20% english and 80% urdu (I do not speak urdu, so I think you can appreciate where I am coming from).

What 3 things do you wish people would understand about you when you experience sensory overload?

1. That I need time to myself to take control of the situation and calm myself down.
2. That I do not, under any circumstances, need consoling, particularly if it requires people touching me (such as hugs) as it makes it worse. Once I am over it, hugs are acceptable.



3. That I am unlikely to socially engage properly owing to my inability to apply my full concentration to what is being said to me.

What 3 things do you wish people would do for you when you experience sensory overload?

Do not interact with me, do not touch me and give me some space.

What 3 things help you to prevent sensory overload?

1. Avoidance of the situations that create the sensory overload in the first place.
2. If point no.1 is not applicable, ensuring that the stressful situation passes as quickly as possible before the sensory overload occurs.
3. Not entering into the stressful situations alone, but with people who understand me so I can be removed from the situation as quickly as possible should I start to feel overwhelmed.

What 3 things help you to recover from sensory overload?

It depends on how I feel really. Ultimately I:

1. Must be removed from the offending situation as quickly as possible.
2. Must be in a quiet area with no people or very little people.
3. Doing any hobby or activity that I feel like at the time that will take my mind off the stress I feel. It could be anything, such as listening to music, yoga, reading a book or playing a computer game.

JMNIXON95

2. What does sensory overload feel like?

Extreme anger.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

I'm frustrated and don't feel like talking.

5. What 3 things do you wish people would do for you when you experience sensory overload?

I wish they would leave me alone.

GRAMIREZ

For me, it's "GET THE F*** AWAY FROM ME, OR YOU'RE GOING TO GET HURT!"

SEARCHFORSERENITY**1. What 3 things that lead to sensory overload for you?**

Lights (fluorescent, computer screens, even the brightness of a page while reading) and multiple sounds at once, or certain frequencies, tactile stimulation (being rubbed in the same place, certain fabrics, etc..)

2. What does sensory overload feel like? L

ike I can't breathe, dizzy, lightheaded, headache, anxious, want to get away.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

Stress and anxiety, then exhaustion.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

That I need to get away from whatever is causing it. That I am not upset with them. That I can't function when I'm in overload.

5. What 3 things do you wish people would do for you when you experience sensory overload?

Tell me I can take a break, turn off the lights, sometimes I need people to hold me, other times I need to be left alone in the quiet.

6. What 3 things help you to prevent sensory overload?

Not doing things when I'm fatigued, keeping my sugar up, recognizing when I start to get overwhelmed and getting away.

7. What 3 things help you to recover from sensory overload?

Taking a hot shower, going to sleep, eating or drinking something I really love.

FLYINGDUTCHMAN

This reply has been slightly edited

1. Noisy environment, too many requests at the same time, messy and confusing layouts (visual overload).
2. Getting into panic attack, nervous feelings, anger.
3. Mostly I get angry/moody, or panic. In any way it is difficult to hide.
4. That I just need some time for myself, that sensory overload does not mean I handle all stress badly, I would like to show them what it feels like.
5. At that moment I want to be left alone, no questions/comments of any kind.
6. Quiet environment, cool down when I sense it is a bad day, take regular moments for myself. delay reactions to requests.
7. Sleep, daydream, obsessive thinking.

JODEL

Sensory overload, #1 face to face, or phone interactions with individuals, #2 loud noises, #3 bad smells

I get overwhelmed and distracted, jittery and nervous. Sometimes aggressive.

I can't hold a conversation very well, I get spazzy and over talkative about random things and laugh when it's not applicable

I wish they would know that that's what's happening, I'm just overstimulated not uninterested or crazy

I practice yoga daily, removal of myself from the situation and breathing exercises to help with overall anxiety

I have to stop and think about the situation, realize I'm overstimulated, calm myself down by breathing and clearing my head. Knowing that the environment is too much is half the battle for me. Daydreaming about my favorite topic or obsession at the time helps calm me.

CORNFLAKE

Owww. Too many questions!

What leads to overload?

Sudden and/or very loud noises. Surprises; even nice ones like gifts etc. Unannounced changes to a routine. People trying to touch or cuddle me. Noisy crowds of people chattering away. Kids screaming. "Busy" or pebbled surfaces (like a beach) - way too many patterns going on. People getting angry at me when I have absolutely no idea why but telling me that I do. I don't.

What does it feel like?

Like I've suddenly been wrapped in a reality-insulating blanket. I just shut down and can't feel or react, so I usually just stand/sit absolutely still and stare very hard at something. Sometimes my mind is racing and that's very difficult to pull back.



Emotionally I feel crushed & exhausted and if chattering crowds are involved I also start to feel threatened and angry, so have to leave immediately or I'm likely to lash out.

How do I feel if others expect a reaction while I'm "away"?

Even more anxious/crushed/drained/threatened and as I remain unresponsive or grunt in response, I generally get "the look" - that odd combination of fear/worry/condescension which I just can't work out, before they start moving away - apparently in case they catch whatever it is they're afraid of, going by the expressions and exchanged looks. Well, that's how it seems.

What do I wish they'd understand about it?

You won't catch it and no, I'm not barking mad. Just leave me alone and I'll reboot.

What do I wish they'd do?

Don't look at me and DO NOT touch me. Don't even come close.

What helps prevent an overload?

Keeping away from situations which are likely to trigger it (see first answer) - but I still get caught out.

What helps me to recover?

Leaving me alone for a while. I just need to sit quietly as I refocus.

NARKITO

This reply has been slightly edited

Please, do consider that English is not my first language.

Not bothered by the number of questions, but not sure how to answer them all.

1. What 3 things that lead to sensory overload for you?

Brightness in general, it can be artificial or natural light especially if combined with intermittent lights or flickering.

Noise, especially high pitched ones.

Some fabrics, especially the ones that don't breath well.

2. What does sensory overload feel like?

It feels like being very tired but having something bothering you not allowing you to get the much deserved rest. And that makes me angry, very angry. I also feel helpless and like someone has to do something NOW.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

Like I need to give them some sort of (polite) answer and just endure it until I can flee the scene. But as more time passes and I can't seem to get out, I start losing my "filters" and awful things come out of my mouth, eventually I just walk out with no full explanation. It rarely happens, 'cause I'm pretty good at saying "hey, I need a brake", but it has happened.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

That in that precise moment I'm not thinking through what I say, so most things that sound like insults, are not really thought to be exactly that, that I'm mostly trapped in a mental place where all I want is to GET OUT. And that I need someone to watch over me for a bit, but in silence.

5. What 3 things do you wish people would do for you when you experience sensory overload?

If I say I need a break now, it does not mean I can wait 10 more minutes, it means now. If I ask someone to lower their voice or just keep quiet for a few minutes, it doesn't mean I want them filling the space with random remarks about the architecture of the building or lowering their voice for one sentence and then speaking at normal volume again. Also, that is not something I want to happen to me, but it does and it's very exhausting.

6. What 3 things help you to prevent sensory overload?

Sunglasses, noise cancelling headphones, 100% cotton clothes and preparation, knowing in advance where I'm going, what are we doing, where the exits are, and such.

7. What 3 things help you to recover from sensory overload?

Laying down, closing my eyes and enjoying the silence. If laying down is not possible or the place is too noisy, then walk around with music loud enough to drown the back noise and stay silent or talk only for very important things (say someone asks if I'm allergic to something in the menu, I have to answer, but if I'm asked something that need a no or yes kind of answer, I just nod).

Mostly I just need to slow down and get some rest.

STEELMAIDEN

1. loud noises, soft touch and bright light
2. like someone is drilling a hole into my skull and stamping on my chest
3. I run away and go into a panic state
5. take me away from the source
6. ear muffers to block out sound and sunglasses
7. rocking back and forth in a quiet, dimly lit room (i.e. my bedroom)

PATIENT_ANONYMOUS

This reply has been slightly edited.

Hi, I said I'd try to get to this even though my head's all fuzzed. My answers may be kind of random as a result. Also, you're looking for three answers for every question so because of "fuzzy head" or maybe just the question alone, I may not be able to think of three.

(This respondent, who also suffers from epilepsy and PTSD, was recovering from a series of seizures when she wrote her reply.)

1. What 3 things that lead to sensory overload for you?

- Being touched by strangers or other people that I have not "chosen" to enter my own physical space.
- Loud, public environments such as pubs, rock concerts etc... where there are too many people (yet a more controlled and quiet space like going to see the a symphony orchestra is fine.)
- Having to attend social functions when I don't care to, however am obligated and must engage with people and talk about boring, pointless things.
- Unpredictable emotional triggers that I cannot know anything about, they may or may not toss me into COMPLETE overload. Who knows?*

2. What does sensory overload feel like?

- Frustration, anxiety and nervousness, a need to somehow control my environment, exhaustion.

3. What effect does it have on you when people expect you to engage with them while you experience sensory overload?

- I can't answer this question because I don't know when or what peoples' expectations are when I engage with them. Either when I'm overloaded or not.

4. What 3 things do you wish people would understand about you when you experience sensory overload?

- I can't really answer this question either because the "people" that already know I'm an Aspie already understand things. To extrapolate and give you some answers that might be helpful overall? Be patient, let me set the boundaries and rules, if you will, and take things at my own pace, not judge me(???) not get frustrated, let me do whatever it takes to get through it? I'm not sure. If you mean "people" as strangers, how can they understand anything about me? They don't know anything about me! The only answer to that is, they understand Asperger's and the Spectrum.

5. What 3 things do you wish people would do for you when you experience sensory overload?

- This is sort of like the answers I gave above. The only other thing I can think of here is let me communicate with a pen and paper if/when I go non-verbal.

6. What 3 things help you to prevent sensory overload?

- Wearing my iPod all the time when on public transit etc... to shut out other peoples' voices, mobiles ringing.
- Stimming whenever and wherever I need to if I start to feel overloaded.
- I just bought a weighted blanket so that should prove useful (for me at least, maybe not everyone.)

7. What 3 things help you to recover from sensory overload?

- Lots of rest.
- Using that weighted blanket I just bought? Should help?

*A sad but very honest answer. That is why I added a fourth point to your first question.

"Sensory Issues" vs. "Sensory Overload" mean two different things to me. I can deal with my "Issues" due to maybe coping mechanisms I've developed. Sometimes this borders on OCD-like behaviour to calm me down or "set things right" in my head. As above, sometimes I just stim away until I can relieve some of the tension I am feeling. But for this answer, when things get REALLY bad, you get so overloaded you reach a point of no return.

That is a meltdown! And it's the only way (for me) to EVER recover! Different for everyone but I'll be sobbing for ages and ages, I'll be stimming in whatever ways, I'll be perseverating, I could be curled up in a tiny ball, still crying like crazy, unable to move at all! It's so unbearable I can hardly reach for a tissue to wipe my nose! I'll just keep using my sleeve!

You are reduced to feeling like one, big baby. For mine, so far, all have lasted up to, at the most, two about hours, think? Then, of course, you are totally exhausted. And still feel like you're a piece of crap. And still feel like it was all your fault for whatever started it in the first place! Again, for me. I don't know how long it's taken me to recover from the latter.

Does any of that help?