

# Identifying Mental Health Problems in Autistic People

## Snapshot

- This section describes common mental health problems experienced by Autistic people.
- We identify common "body", "doing" and "thinking" signs of mental health problems.
- For Autistic people, the combination of stressors and mental health problems can lead to meltdowns, shutdowns, or burnout.

**It is important to note that this is not a diagnostic manual.** There are many mental health problems that are not discussed here, as this guide's goal was to touch on some of the more common mental health problems Autistic adults may experience. Noticing the signs may help people to seek help or support. A lot of the signs can occur in more than one mental health problem (e.g., weight loss or gain can be a physical sign of eating problems or of substance misuse).

**Content warning:** Parts of this section talk about identifying physical experiences, behaviours and feelings that Autistic people may experience. The content described here does not reflect all Autistic people's experiences.

There is content in the Autistic experiences boxes that may contain topics including medication, trauma, abuse, suicide or assault. It could be triggering for some people.

The visuals and texts are not meant to suggest that an Autistic person has any of, many of or all of these issues; rather, these are the kinds of mental health problems that can be seen when Autistic people seek help for their mental health.

## Knowing your own “usual”<sup>a</sup> (knowing you)

Understanding your own “usual” is just as important as knowing what good mental health means and what it looks and feels like. **Someone’s “usual” (also known as “baseline”) is how they are on a typical day.** This includes their usual preferences, feelings, social interactions and activities.

Your “usual” (or baseline) is how you are on a regular day. It is different for everyone.

It can be helpful to know your own usual and let others know what your usual is. Otherwise, people may think there is something wrong when, in fact, there isn’t.

Usual is different for every person. One Autistic person’s own usual is different than another Autistic or non-Autistic person’s usual. A person may notice that their feelings, social interactions, activities and preferences change when they are experiencing poor mental health. Mental health problems change what is usual. In some cases, because of mental health challenges, trauma and long-term bad circumstances, “usual” may not always mean good mental health.

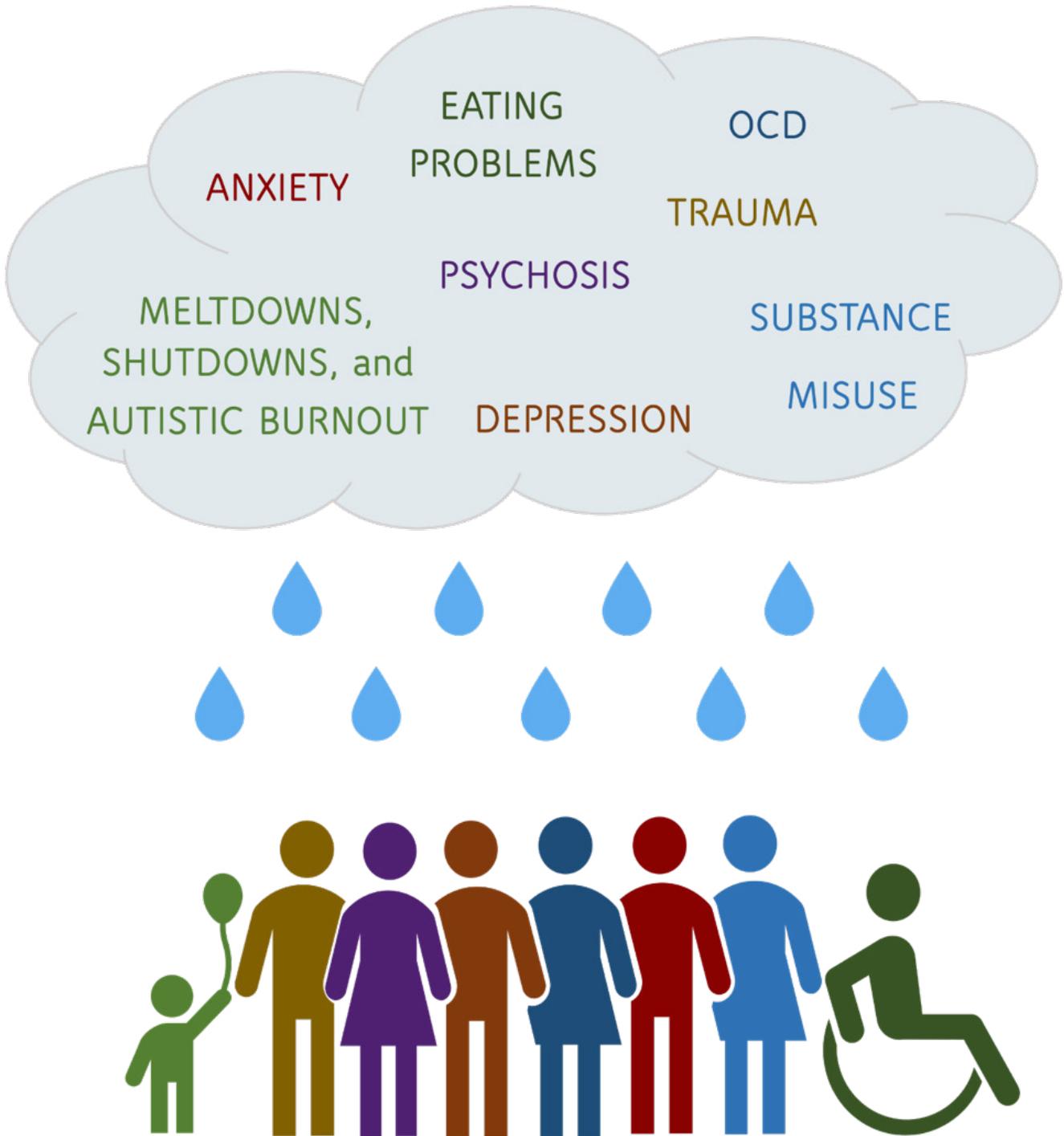
Knowing your baseline is very valuable in terms of mental health. When a person first notices changes in their usual self, it can signal them to check in about their mental and physical health. In doing so, they can notice if things are going well or not. This may prompt a person to take steps to help themselves or reach out for help if they determine their behaviours and responses are outside of what is usual for them.

It can be helpful to understand what usual is for other people, along with knowing your own. Again, **everyone is different, and that is okay!**

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<sup>a</sup> The concept of “Knowing your own usual (knowing you)” was inspired by the *Know Your Normal Toolkit* created by Ambitious about Autism (2019).

# What are some mental health problems Autistic people can have?



## Anxiety

Every person feels nervous, scared and anxious about things from time to time. Everyone experiences anxiety—both helpful and unhelpful kinds. **It can be useful to have fears and be nervous**; it can help people to be aware of and avoid danger and stay safe. Anxiety is an emotion that is especially useful when needing to notice dangers in the world (e.g., “Watch out for that car!”)—this is **useful anxiety**. For most people, when the trigger of the anxiety is no longer there, the anxiety ends, too. They no longer feel the uncomfortable symptoms that can go with anxiety, such as a sense of danger, rapid breathing and pounding heart. Autistic people are often marginalized, vulnerable and sensitive to their environments, and their anxiety is often triggered for valid reasons. It is important that people do not invalidate an Autistic person’s anxiety.

**People can also have unhelpful anxiety**, which includes anxiety that does not end even when the causes of it are no longer there or anxiety that does not help a person figure out what is dangerous or stressful about their environment or situation.

Anxiety can be unhelpful if it leads a person to avoid things that the person would like to do. Unhelpful anxiety can stop people from being at their best, whether it be at work, in relationships or in managing their daily activities. Anxiety can be a problem when feelings of fear, worry and even panic **become overwhelming**, and if a person feels that the feelings are **out of their control**.

### Unhelpful anxiety can:

- continue even when the cause has stopped
- be unhelpful in identifying what is dangerous or stressful
- make you avoid things you like to do
- stop you from being able to do your best
- make you feel overwhelmed and out of control

People can have anxiety about many different things. Some people have anxiety when they think about scary things that may happen in the future. Others may be anxious specifically about being in social situations, open spaces and crowds, or about the thought of a panic attack. They may have anxiety and fears about specific topics (such as animals, harsh weather or their personal health) or situations (such as getting a needle). Autistic people may have more reasons to feel anxious or be more at risk for anxiety because of their lived experiences.

## What does anxiety typically look like?

There are lots of potential signs of anxiety. Remember, just because a person can experience some of these signs does not make them bad, negative or wrong. They are just some possible signs that a person is feeling anxious.

Some Autistic people may be anxious and still not show these signs or may show only one or two of them. It is important to know that these same signs may not be anxiety and could be mistaken for anxiety (e.g., a person may be hungry or may have had too much coffee). But when a person feels anxious, they often show some of these signs. So, “knowing your own usual/baseline” (and others knowing it, too) is important.

### Signs of anxiety<sup>1</sup>

Following are some of the common signs of anxiety that people can experience. It is not only Autistic people who experience these signs—everyone who experiences anxiety can have different “body,” “doing” and “thinking” signs.

Body signs	Doing signs	Thinking signs
<ul style="list-style-type: none"> <li>• Heart racing fast</li> <li>• Chest pains</li> <li>• Breathing heavily or shortness of breath</li> <li>• Dizziness/light-headedness</li> <li>• Having a lot of energy</li> <li>• Hands shaking</li> <li>• Knees feel shaky or weak</li> <li>• Dry mouth</li> <li>• Sweating even if it's not hot</li> <li>• Having “butterflies” in stomach</li> <li>• Sweaty hands</li> <li>• Sweaty armpits</li> <li>• Feeling nauseous or sick</li> <li>• Gastrointestinal issues (diarrhea, heartburn, etc.)</li> <li>• Neck and shoulder stiffness</li> <li>• Acid reflux, belching or burping</li> </ul>	<ul style="list-style-type: none"> <li>• Meltdowns and shutdowns</li> <li>• Insisting upon certain routines to avoid bad things from happening, when they are unlikely to happen</li> <li>• Stimming to help calm when feeling anxious: body rocking or flapping, etc.</li> <li>• Leaving anxiety-producing situations</li> <li>• Arguing</li> <li>• Pacing</li> <li>• Physical self-harm, such as skin picking, nail biting, hair pulling or head banging</li> <li>• Being less social, asking others for space or wanting to talk about a problem</li> <li>• Cancelling plans with family or friends that the person typically attends</li> <li>• Wanting to go to the bathroom</li> <li>• Over-talking</li> <li>• Information seeking</li> <li>• Appearing vacant</li> <li>• Going rigid</li> <li>• Becoming very still and quiet</li> <li>• Acting out toward others or their environment</li> </ul>	<ul style="list-style-type: none"> <li>• Getting stuck in thinking over and over again (also known as “ruminating”) that something distressing will happen</li> <li>• Only seeing the negatives when there are also positives</li> <li>• Trying to plan for every possible outcome of a situation</li> <li>• Thinking may become overwhelming or out of control</li> <li>• Feeling scared without a reason to be scared</li> <li>• Slowing down of productive focusing</li> <li>• Having trouble focusing</li> <li>• Feeling agitated</li> </ul>

## What are some common triggers of anxiety for Autistic people?

- **Uncertainty**

Not knowing what is going to happen next or how others will act or how one is supposed to act can be challenging and upsetting. For Autistic people, this uncertainty may be threatening, especially when there are no clear plans or explanations of what will happen next. Many Autistic people prefer to know what to expect and what is expected of them. When they have uncertainty instead of predictability, it can contribute to or trigger anxiety.

- **Changes**

Changes or transitions in day-to-day life are disruptive, and for some people, these changes are incredibly stressful and hard to manage. Changes in schedules, routines or the environment, especially when unplanned, can contribute to or trigger anxiety.

- **Sensory experiences**

The majority of Autistic people have sensory and motor processing differences. Some people are very affected by these experiences, and others are less affected.

Sometimes, the experience of the environment triggers anxiety when the sensory demands are not well-matched to sensory needs. Sensory experiences that are understimulating or overwhelming can happen anytime or anywhere, and it can be stressful and increase anxiety.

For example, some Autistic adults have described the following as anxiety triggering:

- **Visual** – bright lights (e.g., florescent lights)
- **Sounds** – a baby crying, certain people's voices, white noises (ambient sounds), crowds at a mall, a revving engine, hand driers, traffic, chatter at a party or people talking really loudly
- **Smells** – new packaging smell, new carpeting at the office releasing odour, perfume or cologne, hair product, washrooms or food may be strongly aversive. Or a person might be triggered by smelling people, food or other things in their environment.

- **Touch** – food textures, an unexpected hug or kiss on the cheek, being tapped on the shoulder, certain fabrics and textures of clothing, getting water on the skin such as when it rains, getting a massage, or massaging shampoo into the scalp.
  - **Taste** – strong tastes, either soft or hard textures
  - **Interoception** – feeling any difference in heart rate, unexpected rises in their beats per minute, awareness of appetite or thirst or bowels or bladder
- **Social situations and expectations**

When expectations are not clearly communicated or do not fit with an Autistic person's way of understanding, they may feel anxious. Some Autistic people may feel anxious about their performance or how they appear to others or about being forced to behave or mask their personality. This can be especially triggering in social situations where a person does not feel accepted, where they are being judged or where they are expected to communicate in ways that are not comfortable or well-suited to them.

Some Autistic adults may not always understand the hidden expectations of dating, the workplace or social opportunities. In these situations, an Autistic person could be shamed by those around them, which can naturally lead to being anxious about those situations. For example, if they act in a way that others see as “weird”, “rude”, or “self-centred”, and react to them in negative ways rather than supporting them. When expectations do not match the skill level, anxiety can increase.

- **Specific fears**

Specific fears (also called phobias) are common and can make everyday life more difficult. These fears may stop a person from doing what they would like to do or would usually do, because a person may be afraid that they might have to interact with the source of the anxiety.

People can have unique fears that other people may not typically be afraid of. Fears may include dogs, needles, public speaking, heights, planes, vacuum cleaners, balloons, public bathrooms, meeting new people or meeting groups, but there is no limit to the kinds of fears that people can have.

## Autistic experiences with anxiety

“When I was a senior in high school, I’d become so fearful of committing more faux pas with my classmates and getting unwanted attention from guys that my school days consisted of going to class, being there for that class period and then leaving the class immediately.

“As I’ve mentioned before, I also felt deep down in the pit of my stomach that if I was to try to explain my side of the story and Asperger syndrome, [it] would not have been taken seriously by my classmates and things might end up worse for me if I did. That fed into my spending time in the class only as long as I needed to and not sticking around, which had become my self-imposed strategy to minimize, if not eliminate, my chances of committing more social faux pas with my classmates and getting unwanted attention.”

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“My panic attacks started when I was nine, and they really forced me to get to know myself, my baseline, my triggers and my emotional awareness. While I really identify with my autism, I really don’t identify with my panic disorder. Autism gave back to me in skills and strengths, but panic disorder really hurt and made it hard to enjoy things I typically liked or wanted to do. Panic disorder didn’t make me strong; I got strong because no one else was going to handle my panic attacks for me, and because I wanted my life back.”

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“There are difficulties of keeping on the mask in order to not be crucified, but I’m finding the older I get, the more difficult it is to play the NT [neurologically typical] role. When I was young, masking my differences was a huge source of anxiety. Masking my struggles with verbal direction . . . waiting for other children to follow the directions and watching them before mimicking them and faking it until I could figure it out. So many gym class games were so difficult. All verbal rules directed in an echoing gymnasium with bright-white linoleum floors and the anxiety of being seen as ‘dumb’ or ‘stupid.’ I faked it. I faked it hard.”

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“It wasn’t until about Grade 5 or 6 that I finally figured out all the rules to the games they played in gym class . . . basketball, dodgeball, soccer, etc. It took years of inventory and careful study of observing others’ behaviours in these games to get it. So, the anxiety started very early—right from kindergarten, always faking, always masking. That anxiety was very early on my ‘usual.’ So, ‘knowing my usual’ is not really what should be my ‘normal.’”

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“My biggest triggers for anxiety are (1) expecting to have to deal with certain kinds of ableism and (2) unclear instructions. Both of these are very much related to anxiety about uncertainty and change. I often get anxious about uncertainty or change, but it’s not the uncertainty or change that’s the primary source of the anxiety. It’s that I don’t know the ‘appropriate’ social rules and have to worry about the consequences for doing something ‘wrong.’

“Of course, uncertainty and change by themselves can be primary sources of anxiety for some Autistics. But sometimes it’s ultimately the uncertainty regarding figuring out how to conform to ableist expectations and social rules in uncertain or changing environments that are the root of the anxiety.”

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“One trigger I have for anxiety is when co-workers are looking at me and whispering to each other or laughing and staring at me, or when people suddenly get quiet when I come into a room, or when someone makes a veiled threat to my livelihood or my character reputation—then my anxiety spikes very high. Also, during almost all social interactions I invariably sweat a lot, so I try to wear clothes that conceal underarm sweat.”

## Depression

Everyone gets sad and down sometimes, especially as a reaction to challenging situations in life. **But sometimes people experience a kind of sadness that is not simply a reaction to specific situations but rather, it goes on and on,** growing into a long-lasting feeling of sadness and hopelessness (which means having or feeling no hope). Hopelessness can lead to someone giving up on life, leading to suicidal thoughts, which can then lead to suicidal plans and actions. These feelings and thoughts can cause problems in life and take away from the person’s potential to thrive.

Depression is a mental health problem that is commonly experienced by Autistic people.<sup>2</sup> It's important to note that any signs of depression should be compared to a person's own sense of their usual mood and behaviours. For example, if someone in their usual state does not have a big appetite, then a loss of appetite needs to be compared to their usual state.

Depression can occur when a person gets stuck focusing on negative things that happened in the past—what should have been or could have been, and what used to be (this is called rumination). Some Autistic people may ruminate or “loop” on social mistakes or on times they were excluded, teased or bullied or

**Hopelessness** is a key part of depression.

did not receive a job offer or promotion. They might be dissatisfied with their lack of social connections or disappointed in not finding or keeping a relationship or employment. Over time, these life experiences can build up.

**Grief is not the same thing as depression. Grief is a part of life, and everyone grieves in their own unique ways.** Grief is a feeling that comes when we lose something. It is complex, and any loss can cause grief. Some people may react to grief with a lot of emotions, and others may not. Some people experience grief right after a loss, or it may begin weeks, months or years after the loss.

**Autistic people also grieve but may not always express it the same way as non-Autistic people do.** Some Autistic people's grief may look more like Autistic traits (such as higher sensory sensitivity or intense focus on a topic) or they may have no reaction. They may also want more alone time to process the loss, instead of talking about it, and it may last for longer than others expect. These reactions can affect mental health, as it can worsen their experiences of anxiety, trauma or depression. But grief is not a mental health problem. It is a natural reaction to loss. Everyone deserves support when they are grieving.

## Signs of depression<sup>2</sup>

Depression and anxiety are two states that often happen together. It is sometimes hard to notice whether someone is depressed without asking questions or looking for specific signs. Following are some potential signs:

Body Signs	Doing Signs	Thinking Signs
<ul style="list-style-type: none"> <li>• Weight loss or gain</li> <li>• Scars from self-injury/self-harm</li> <li>• Changes in sleep: Increase in the need to sleep, or feeling like sleeping much less than is usual</li> <li>• Always feeling tired or having aches and pains</li> <li>• Changes in appetite: Being hungrier than usual or not as hungry as usual</li> </ul>	<ul style="list-style-type: none"> <li>• Eating less due to loss of appetite</li> <li>• Overeating due to increased appetite</li> <li>• Increase in social withdrawal or isolation: <ul style="list-style-type: none"> <li>→ Cancellling plans with family or friends that the person typically connects with</li> <li>→ Staying alone in the room or apartment for days when this is not usual for the person</li> </ul> </li> <li>• Avoiding social situations that the person usually feels able to take part in</li> <li>• Being overly irritable or aggressive for reasons that are not usual for that person</li> <li>• Lower productivity</li> <li>• More, or less, stimming than is usual</li> <li>• Sleeping a lot more or less than usual</li> <li>• Extreme increases in disorganization from lack of motivation for everyday responsibilities, including basic tidying (e.g., clothes all over the floor)</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of interest in things that are usually pleasurable</li> <li>• Loss of motivation to do things that the person usually does</li> <li>• Feelings of sadness and being overall down and 'blue' that do not go away</li> <li>• Feelings of hopelessness: <ul style="list-style-type: none"> <li>→ "Nothing will ever change"; "It will always be this way."</li> </ul> </li> <li>• Feelings of exhaustion for no physical reason</li> <li>• An increase in being focused on certain topics and not being able to shift off of them the way the person usually could</li> <li>• Inability to feel joy and other positive emotions; unable to look forward to anything</li> <li>• Increased obsessive thoughts or suicidal ideation</li> <li>• Suicidal thoughts</li> </ul>

### Autistic experiences with depression

"Many of my stims are pleasure/feel-good stims to mitigate tough situations or when I'm feeling overwhelmed by stimuli. One of my big signs of depression is that I don't do any of these things to help me self-regulate because I can't be bothered and it's too much effort/energy. The loss of stims is a huge sign that I'm depressed."

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“In some ways I saw myself as a survivor; getting through depression and anxiety wasn’t always pretty or convenient, and at times I scraped and crawled and fought dirty, but I made it.”

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“When I was 13, my GP tried to put me on an antidepressant, but for whatever reason it didn’t seem to be working in my opinion, so I threw them out. I was too young to figure out what to do on my own, and there were no adults who knew how to help me at that time. A decade later, things got bad enough again that I asked about medication for depression. After trying all the classes of typical antidepressants and finding that none of them worked and often had awful side-effects, I happened to try that first atypical medication again but in a lower dose, and it worked, so I stayed on it for a few years before feeling confident enough to taper off and function without it.”

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“I find I cannot pull things together. Like, my brain doesn’t work as well. Same with anxiety. I just cannot get anything mobilized. My executive function is out the window, when it already struggles from sensory issues.”

## Trauma

**Trauma** is “an event that damages or harms the individual even though the severity, longevity and permanency of that harm may vary widely.”<sup>3</sup> Things that distress or traumatize an Autistic person can be very different from what may be distressing or traumatic for many non-Autistic people.

**Trauma** is an event that hurts someone. How severe, long or permanent that harm is can be different for each person.

**Being Autistic can make it more likely that a person will experience stressful events, which can increase the chance of trauma.** Stressful social events, like being bullied, attacked, rejected or segregated, can lead to harm. Changes to schedules, hard transitions, being stopped from doing behaviours that are pleasurable or calming, or being prevented from engaging in preferred interests, can also be traumatic, especially when it happens regularly.

Service providers may receive very little training to work with Autistic people around mental health and trauma. Signs of **trauma may be overlooked in services that are designed to support an Autistic person, which can make the support services unintentionally traumatizing themselves.** There can be trauma when a person is not listened to or repeatedly told that there is nothing wrong, when they know that there is. As one adviser said: “There must be a way to support Autistic people without sending them to the emergency department, only to be revictimized there.”

“It can also be dangerous for Autistics to seek health care, especially mental health care, if they cannot be certain that Autistic- and trauma-informed allies will receive them.”

## What are some common responses to trauma?

Some common experiences and responses to trauma include<sup>4</sup>:

- **Emotional**

Emotional reactions to trauma vary greatly and are influenced by a person’s background. The most common reactions are anger, fear, sadness and shame. People can also experience the emotions very intensely (and be overwhelmed by it) or be unable to experience any emotion (and so may feel numb). Some people may have difficulty noticing, labelling or dealing with these feelings.

- **Physical**

Trauma can lead to negative physical experiences like sleep problems, muscle pain, breathing pain, gut and stomach issues or skin picking (leading to skin conditions). Physical experiences may become chronic if they are not addressed.

- **Psychological**

Traumatic experiences can change the way a person thinks about and sees themselves, the world around them and their future. Some people who experience trauma may see themselves as helpless or incapable. They may think that the world is unsafe, people are dangerous or there is no meaning to life.

- Behavioural

Responses to trauma are very different for each person. Many times, people will do things to avoid or cope with the intense emotions that come with trauma. Some people may self-medicate by using drugs or alcohol. They may engage in risky behaviours, overdo activities that feel good or are part of their usual routine or turn to harming themselves as a way of coping with their distress.

- Social/Interpersonal

Trauma also affects relationships. Some people may want to reach out for support, and others may isolate themselves from their friends, families or support systems. They may do so because that is how they manage trauma, and if others don't understand their coping approach, this can affect their relationships. Sometimes, reaching out for support can cause more harm, especially when the person is misunderstood.

## What is posttraumatic stress?

Autistic people experience trauma significantly more than non-Autistic people. This can lead to stress that lasts long after the trauma, or **posttraumatic stress**. There are three types of posttraumatic conditions that are reported to be commonly experienced among Autistic adults, though not everyone has access to a formal diagnosis:

1. posttraumatic stress disorder
2. complex posttraumatic stress disorder
3. developmental trauma.

Sometimes trauma can happen because of a single event. Other times it develops over time.

## What is posttraumatic stress disorder (PTSD)?

**Posttraumatic stress disorder** refers to ongoing negative emotional and psychological reactions that are caused by specific events in a person's past.

**Posttraumatic stress** is stress that lasts long after a harmful or traumatic event.

It is triggered by witnessing or experiencing a frightening or life-threatening event, such as a catastrophic car accident, a natural disaster or a physical assault. A main feature of PTSD is that the traumatized person psychologically re-experiences the traumatic events.

### Posttraumatic stress disorder

is the most well-known post-traumatic stress condition. It is caused by specific events in a person's past and a main feature is **flashbacks**—reliving the events.

## Signs of PTSD<sup>4</sup>

Following are just a few of the common signs of PTSD that people can experience. It is not only Autistic people who experience these—everyone who experiences PTSD may have a variety of the different body, doing and thinking signs.

Body Signs	Doing Signs	Thinking Signs
<ul style="list-style-type: none"> <li>• Aches and pains:               <ul style="list-style-type: none"> <li>→Migraines (headaches)</li> <li>→Chest pain like a heart attack</li> <li>→Back aches</li> <li>→Stomach aches</li> </ul> </li> <li>• Acid reflux</li> <li>• When reliving what happened, the person may feel nauseous, sweaty or shaking, or their heart may beat fast</li> <li>• Becoming numb (person stops receiving bodily cues)</li> <li>• Not feeling in touch or connected with bodily sensations</li> </ul>	<ul style="list-style-type: none"> <li>• Being easily irritated or aggressive</li> <li>• Avoiding people, places and activities that remind the person of the event</li> <li>• Having sleep problems</li> <li>• Using alcohol or drugs to feel something</li> <li>• Needing to always feel busy</li> <li>• Having difficulty concentrating on daily activities</li> <li>• Participating in risky activities or putting one's self in dangerous situations</li> <li>• Not expressing a lot of affection</li> <li>• Expressing less interest in things the person enjoys</li> </ul>	<ul style="list-style-type: none"> <li>• Feeling very alert, jumpy or on the edge</li> <li>• Feeling very distressed and confused</li> <li>• Feelings of anger, shame, sadness or guilt about the event or about themselves</li> <li>• Feeling disconnected from what the person is really feeling</li> <li>• Feeling alone</li> <li>• Difficulty believing what has happened               <ul style="list-style-type: none"> <li>→Feeling betrayed and unsafe</li> <li>→Having a hard time remembering details</li> </ul> </li> <li>• Intense flashbacks to what happened               <ul style="list-style-type: none"> <li>→Experiencing nightmares replaying the event</li> <li>→Being triggered by specific memories that remind the person of the place, the sights or sounds from the event</li> </ul> </li> <li>• Having blackouts (no memory of the day or period of time the traumatic event occurred)</li> </ul>

## What is complex posttraumatic stress disorder (C-PTSD)?

### Complex posttraumatic stress disorder

is when a person experiences multiple, repeated and long-term trauma (like ongoing bullying, verbal, physical or sexual abuse). The *ICD-10*<sup>b</sup> included a diagnostic category called Enduring Personality Change after Catastrophic Events to describe this experience. The main difference from the PTSD signs described above is that with complex posttraumatic stress, **a person may also change in their personality in an ongoing way**, beyond things that remind them of the harm they experienced. It affects how they see themselves and how they manage stressful events. Autistic people can experience PTSD and C-PTSD at the same time.

**Complex posttraumatic stress** is caused by long-term trauma, like ongoing abuse, and can result in personality change and dissociation.

C-PTSD is also associated with repeated social injury over time, where the victim feels they have no chance to escape. For Autistic people, they may be forced to go to schools or supports where the sensory and social demands are overwhelming; where they are teased, bullied, rejected and shamed—and they are forced to do this regularly over a period of years.

Sometimes people with C-PTSD may feel permanently worthless and that nobody can understand what happened, or they may regularly have suicidal feelings. Because of the ongoing causes of trauma, they may experience what is called “**dissociation**”—where they become “disconnected from the here and now.” People describe the sensation or experience in different ways, such as feeling disconnected from the environment they are in or from their own body. Some may “zone out,” “space out” or have no memory of what just happened.

Though people can at times experience some disconnection in this way, people who experience extreme anxiety or stress may be at greater risk for these symptoms. When they occur frequently, it may cause distress for the person. The experience happens without warning or sometimes without a person being aware that it is happening.

<sup>b</sup> *ICD-10* refers to the *International Classification of Diseases*, 10th Edition, which is published by the World Health Organization.

## What is developmental trauma?

**Developmental trauma** is a term that is less widely used. It refers to how early experiences in childhood can lead to trauma in adulthood. Experiencing abuse as a child, like physical, sexual and/or emotional abuse, can last with a person into adulthood. Autistic people are at greater risk of interpersonal victimization—of experiencing sexual victimization, physical abuse and emotional abuse compared to non-Autistic people.

**Developmental trauma** refers to how early experiences in childhood can lead to trauma in adulthood.

Autistic adults have written about being traumatized by others' behaviour toward them, such as being bullied, teased, berated and devalued.

**Invalidation** happens when a child regularly learns from their environment that their feelings and experiences are disapproved of, are perceived as wrong and are misunderstood, or they learn that they do not matter to others. As this child ages, they can have stronger and stronger beliefs of being worthless which can lead to many mental health problems. Some Autistic people have described how they experienced harm as a result of their interactions with the school system, and that it has led to trauma.

**Invalidation, childhood abuse and harmful autism interventions** can cause developmental trauma.

**Early experiences of treatment in childhood or adulthood may also be traumatizing for an Autistic person.** For example, some Autistic adults have written about how their early experiences with Applied Behaviour Analysis have traumatized them and have led to mental health problems as adults. Others have noted the negative effects of psychotherapy or medications, as well as the harm caused by being unable to consent to treatments and interventions. Interventions that require someone to change who they are, or how they behave, can change how a person sees themselves, how they interact with others and how they navigate their future.

Other Autistic adults have written about the trauma they experienced as a result of going to the emergency department or being hospitalized, or as a result of their interactions with police. The trauma often stems from the lack of understanding and mischaracterization of Autistic people's experiences.

**Content warning:** Some of the experiences shared here may contain traumatic experiences related to medical errors, abuse, school and sexual assault.

## Autistic experiences with trauma

“My experiences with trauma go through elementary school to high school and beyond. One major event I had trouble with is being threatened with the ‘time out’ room, where there was no handle on the inside of the door, just a steel pad. I would have been left alone. The room was carpet-padded up to six feet in height. With an opposite window to an adjacent hallway. I was too young and small at the time to see anybody out of it. That was one main event in elementary school that was traumatic. I had a big fear of being left alone at the time.”

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“Autistic people, particularly Autistic non-binary people and women, are at higher risk of sexual abuse and child sexual abuse. We really need people to believe us and to be on the lookout for us.

“When I disclosed to my therapist as a teenager that a family member was sexually abusing me, her first words were to ask me if I somehow ‘provoked’ him. She never believed me or trusted me. She is now the director of the mental health centre where she works. The male police officer that my school reported the incident to also asked me if I encouraged my family member. I wonder if the fact that I had documented mental illness, that since my therapist’s notes said I ‘struggled socially,’ they thought I must have welcomed or instigated the abuse somehow.

“In many ways, the adults in my life I reached out to for help caused me more trauma than the actual sexual abuse itself. To this day, I have immense distrust of most mental health professionals and law enforcement authorities. They have let me down as a victim and survivor over and over again. Thankfully, I do see a therapist that is actually trauma-informed, after many years of searching. It helps that this therapist has lived experiences that mirror mine. But these kinds of mental health professionals are far and few between.”

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“I have experienced two separate traumas in my life related to medical errors. As a result, I am terrified of doctors and it is very difficult to attend a medical appointment. It has definitely shaped my life. I used to live in fear of getting sick or being in an accident—not because of the illness or accident, but these would mean that I would have to experience the fear of being in a hospital. I was also assaulted. I was in my 20s and had my baby with me. I could not get help for my trauma. It always seemed far too frightening to engage in anything that would make me talk about the events. I could not tolerate the intensity of that emotion. Fear and trauma have made my life smaller than it could have been. I wish I had the courage and capacity to find help and free myself when I was younger.”

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“I believe Autistic people are the true heroes. If it is hard to deal with Autistic trauma and meltdowns—imagine living through them. We are resilient, creative, interdependent and brilliant in more ways than what can ever be shown through a clickbait inspiration-porn news article or blog post. We survive abuse, invalidation, discrimination and systemic barriers day after day.

“For parents, professionals and allies, my advice is to assume that the Autistic person in your life has a degree of trauma. All Autistic people go through traumatizing life events because of how invalidating and unaccommodating the world is to us. We also have a higher risk of being abused and bullied by the people and institutions we interact with. Start trauma-informed, and go from there.”

## Meltdowns, shutdowns and Autistic burnout

Some Autistic people may experience meltdowns, shutdowns or burnout because of stress. While these experiences are not diagnosable mental health problems in themselves, they can contribute to them or worsen existing mental health difficulties. Many stressors and mental health problems can lead to meltdowns, shutdowns or burnout. It depends on each person, their experiences and their triggers.

## What are meltdowns?

**Meltdowns** are described as bursts of overwhelming emotion, which can take the form of anger, crying, screaming, self-harm or harming others, and sometimes environmental aggression (e.g., throwing or breaking objects). They can also be silent, where the person withdraws and may become inactive, slower to respond and unable to attend to anything going on around them. These behaviours are not panic attacks. Meltdowns are intensely distressing, and an Autistic person may have very little control during these times.

**Meltdowns** are bursts of overwhelming emotion and are hard for an Autistic person to control.

Meltdowns are an emotional response to an accumulated or immediate experience in the environment. Too much sensory or social demands that exceed the person's capacity to cope can lead to overload.

Meltdowns can be caused by several factors, including environmental triggers, sensory overstimulation, stress, uncertainty, transitions and rapid change. It is important to note that meltdowns can change over time, not all Autistic people have meltdowns and most meltdowns in adulthood can look like a release of emotion (e.g., crying, sometimes a raised voice).

Educating others in what a meltdown can mean for the Autistic person is essential. Every human is unique in how they like to be supported through a difficult moment. Some need reassurance, some need space, and most people benefit from a calm, non-judgmental approach. Some Autistic people may not want anyone to touch them when they are experiencing a difficult moment. It is important to know how the person wants others to respond if they have a meltdown. It can be helpful for the Autistic person to tell people how they want to be supported if they are having a meltdown.

## What are shutdowns?

**Shutdowns** are sometimes described as “silent meltdowns.” At times, shutdowns can be a short escape from the situation or task. It often involves a person becoming very reserved, caught-up, tired or zoned-out, and less aware of what is going on around them. They may need to go to a less stimulating place, such as a quiet room. Some people may have trouble moving—when they shut down, their movements slow down, and they can become inactive and may need physical

guidance or prompting to move. Others may find it challenging to communicate. Those who communicate in non-traditional ways may be unable to share what they are feeling or what they need. Those who are able to communicate by spoken word may not be able to speak at all.

When a person has a shutdown, it does not mean they are purposely giving the “silent treatment” to others. Too often, verbal Autistic people are accused of being rude or ignoring others when they don’t speak due to a shutdown.

If a person struggles with spoken language during shutdowns or meltdowns, they may need to use other methods to communicate, such as through augmentative and alternative communication devices. Though shutdowns may look less extreme than meltdowns from the outside, they can be just as distressing.

## What is Autistic burnout?

**Autistic burnout** is a broader experience, which might follow a stressful or very exhausting period of time in an Autistic person’s life<sup>6</sup>. This may result from a constant state of camouflaging or being overwhelmed. It is like a “shutting down of the mind and body” and it can take quite some time to recover fully—for some people, it may take months or years. It can lead a person to greatly struggle with ordinary activities such as hobbies, work, self-care or socializing.

Further to this burnout experience, some Autistic adults experience Autistic regression. **Autistic regression**<sup>6</sup> involves the loss of previously gained skills (such as language or maintaining personal hygiene) or social-emotional maturity regresses, sometimes to the extent that the person may act in a childlike way. As one adviser said: “When I am

**Shutdowns** or “silent meltdowns” may involve:

- zoning out
- being less aware of the environment
- needing to leave for a less stimulating environment
- difficulty moving
- difficulty speaking or communicating.

**Autistic burnout** is a shutting down of the mind and body after a long period of stress and being overwhelmed. It results in more difficulty with usual activities and takes a long time to recover from.

**Autistic regression** involves a loss of previously gained skills after a period of burnout. These two terms are often used interchangeably.

under severe emotional stress due to major internal changes (a new brain therapy, for example), I become temporarily functionally regressed in my skills of daily living. I'm not burnt-out, I'm not depressed . . . I may feel like a kid again and vulnerable and 'regress.' Even the quality of my crying is different, more childlike.”

When an Autistic person is under pressure or is experiencing a negative mental health state, they are more prone to experiencing meltdowns, shutdowns, burnouts and regression. Understanding what the mental health problems are, and knowing what to do about them, can help a person to access the help or support they need. In **Section 6**, strategies to promote well-being and how to access support will be described.

If someone is experiencing meltdowns or burnout, it's important that they take the time to heal and recover and that they are connected to people who have the knowledge, patience and support needed to help them do so. When experienced long-term, this can also feed into depression or anxiety and contribute to physical health problems.

### Autistic experiences with burnout

“Often the feeling of burnout is something that can happen with me when I deal with difficult people. Intrusive thoughts—worrying thoughts—about scenarios that probably will never happen, but the compulsions to check on things, for example, is high (autism and OCD). But when things are good, I will feel refreshed.”

“Dealing with and thinking about the people that have made me stressed or have anxiety about makes me feel more burnt-out.”

## Eating problems

Some Autistic people may have a limited diet; in other words, there is a narrow range of foods that they can enjoy or tolerate. The reasons for this vary from person to person. Some people with limited diets may have sensitive stomachs that make digestion uncomfortable or may have sensory sensitivities related to smells, textures and tastes of certain food. Sometimes Autistic people can find comfort in eating the same meal all the time—this does not mean it's an eating disorder. If a person has a limited diet, this is not the same thing as an eating problem or disorder, but it can sometimes develop into one. Most eating problems that develop (see below) do not necessarily begin with a limited diet.

## What is anorexia?

**Anorexia** is a severe eating disorder that affects all genders and usually does not start until adolescence. Autistic women may be at particular risk for anorexia.<sup>7</sup> The symptoms of anorexia include<sup>8</sup>:

1. Limited food or calorie intake, which leads to very low body weight, especially if it's much lower than what would be expected for the person's age and height. People with anorexia generally lose weight by not eating enough calories.
2. Intense fear of gaining weight or becoming "fat" even when the person is underweight.
3. Troublesome experience with one's body shape or weight. A person's weight may be a part of how they see their self-worth, or they may deny their body's fragile state.

**Anorexia** involves restricting calories by not eating, while **bulimia** involves purging of food after eating.

## What is bulimia?<sup>9</sup>

**Bulimia** involves purging food after intense periods of eating (i.e., eating way too much). Purging means that the person gets rid of the food. Purging often happens by forced vomiting after eating, taking laxatives to have bowel movements when it is not needed or exercising too much to lose the calories that were eaten, especially after a period of binge eating. While vomiting or taking laxatives are more obvious, excessive exercise is more accepted in society, and it is harder to see as being harmful.

## What is binge eating?

**Binge eating** involves eating large quantities of food in short periods of time and feeling that the overeating is uncontrollable. It is usually done in secret and even when a person is not hungry. People with binge-eating problems are not always overweight; their weight may fluctuate, and they may not engage in purging behaviours. Feeling embarrassed and guilty is common.

## What is avoidant/restrictive food intake disorder (ARFID)?

**Avoidant/restrictive food intake disorder** is sometimes described as "extreme picky eating," as it is characterized by highly selective eating patterns. This diagnosis was added to the most recent version of the *DSM-5*.<sup>10</sup>

ARFID may come from traumatic avoidance related to food (e.g., choking, force feeding, negative experiences with interventions involving food). People with ARFID may be unable to eat certain foods—they may develop an aversion to the smell, taste, temperature or texture of food. People with ARFID tend to eat a limited variety of foods, which can cause low energy, malnutrition and weight loss. It may sometimes be misdiagnosed as anorexia.

**Binge eating** involves consuming large quantities of food in relatively short periods of time and feeling that the overeating is uncontrollable.

**ARFID** involves a highly selective eating pattern.

## Signs of eating problems<sup>7-10</sup>

Following are just a few of the common signs that people with eating problems may experience. Depending on the type of eating problem, some or none of the below may apply. It is not only Autistic people who experience these — everyone who experiences eating problems may have a variety of different body, doing and thinking signs.

Body signs	Doing signs	Thinking signs
<ul style="list-style-type: none"> <li>• Very noticeable weight loss or gain</li> <li>• Dry skin and brittle nails</li> <li>• Weak muscles</li> <li>• Tooth problems, like discoloured teeth or sensitivity</li> <li>• Thinning hair</li> <li>• Stomach issues (like cramps, acid reflux, constipation)</li> <li>• Irregular menstruation (missing periods)</li> <li>• Dizziness</li> </ul>	<ul style="list-style-type: none"> <li>• Eating in secret, or eating very small or large portions</li> <li>• Eating very fast</li> <li>• Avoiding or refusing to eat certain foods</li> <li>• Lying about whether they have eaten or what they have eaten</li> <li>• Dressing in bulky clothes</li> <li>• Hoarding or hiding food</li> <li>• Withdrawing from social activities (especially if food is involved)</li> <li>• Excessive exercising</li> </ul>	<ul style="list-style-type: none"> <li>• Feeling very anxious about body image, or feeling “fat”</li> <li>• Having a negative self-image</li> <li>• Feeling fearful of gaining weight and worried about eating in front of others</li> <li>• Always thinking about weight, food, calories or dieting</li> <li>• Having difficulty concentrating</li> <li>• Having a strong need for control about food/eating habits; very rigid</li> <li>• Having sensory problems with food</li> <li>• Difficulty feeling hunger</li> <li>• Feeling embarrassed or guilty about eating habits</li> <li>• Feeling a sense of being in control of food and eating habits when everything else seems to be out of one’s control</li> </ul>

## Autistic experiences with eating problems

“Food textures and eating, especially during anxiety, can be a huge problem. I began limiting my food during puberty. The change my body was going through was more than I could handle, and I didn’t have any adults talk to me about it or help me understand what was going on. I didn’t like the change this was doing to my body; I wanted my body to stay the same as how I’d always known it and felt comfortable with it for so many years.

“Controlling my food intake was my way of trying to stop my body from changing and also remove the textural and taste triggers, as well as helped me find a way to gain a bit of control in my life. I struggled with food intake from about 12 years of age until I was approximately 23 years old. Then I was up and down until now. I still struggle with eating when overanxious. Food is just too yucky, and all of my sensitivities increase to make things even less palatable. Now I tend to seek out new tastes a lot more than I ever have before, and in my mid-40s my super-taste and super-smell is starting to reduce a bit, opening up my palette a bit more.”

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“As a former anorexic, a very hyposensitive sense of interoception compounded the problem, as hunger was (and still is) rarely felt. Unfortunately, seeking help for this eating disorder was met with group therapy that wasn’t adapted to Autistic people.”

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“Until professionals learn how to modify treatment for the Autistic person, professionals are going to continue to struggle to help Autistic people to recover from anorexia. I was hospitalized as a teen with an eating disorder, and nothing they said made any difference—until one person happened to say the right thing. It was logical, made sense, and I immediately (and I mean, that day) stopped being anorexic. This is just another example of why we must have only autism-informed and educated professionals helping us when we reach out.”

## Substance misuse and addiction

In Canadian society, many people tend to use substances that have an effect on how they feel or think. Some common examples of these substances include caffeine and sugar that people may consume to get a boost of energy or to become alert. Then there are substances that people take that can change a person's feelings, thoughts and behaviours in a more extreme way. Examples of these sorts of substances include alcohol, nicotine, cannabis, cocaine, stimulants (e.g., amphetamines), opioids (e.g., oxycontin), hallucinogens and other forms of drugs, including prescription drugs, either the person's own or taken from a family member without their knowledge.

The terms “**substance abuse**” and “**substance misuse**” refer to when a person uses these sorts of mind- and mood-changing substances regularly to feel better. **Addiction** means a person may feel that they need to keep taking the substance, even when they do not want to take it (they have cravings for it), and they may need to take more and more of it for the craving to go away.

**Substance abuse/misuse** is when a person uses harmful mind- and mood-changing substances regularly to feel better.

**Addiction** is when a person feels like they cannot stop taking the substance, even if they want to.

Autistic people are at greater risk of developing substance misuse and becoming addicted to substances compared to non-Autistic people.<sup>11</sup> Substance misuse and addictions are more common among people who have experienced trauma and/or have problems with meaningful relationships, employment and financial security. Autistic people often experience these kinds of problems. These things can affect a person's mental health, making them more vulnerable to substances that give relief from the emotional pain they experience.

**Using substances can be a way to feel better or remove negative feelings, such as anger or sadness.** Some people say they use these substances in order to numb their feelings so that they don't feel anything. Doing this is called **self-medicating**. Self-medicating with alcohol or drugs can make situations worse in the long run, even though it feels helpful in the short term.

### What are the signs of substance misuse and addiction?

When trying to understand if someone is using a substance in an unhealthy or dangerous way, there may be some clues in their appearance or behaviours.

But a lot of the time, people hide that they misuse substances. This may be because the substance they are using is illegal or they do not want to get into trouble, or they feel ashamed or bad about using it. Other times, people may not yet realize that they are abusing or are addicted to a substance. For some Autistic people, especially those on a limited income, difficulty or inability to meet financial obligations may be another clue of substance abuse. They may be spending their limited income on their substance of choice.

Quick questions to identify substance misuse:

- **How often?**

Think about how regularly they use the substance. Is it once a week, a few times a week or every day? Do they look for more opportunities to drink or use substances?

- **How much?**

Think about how much they consume: how many drinks they consume daily or how often they use drugs.

- **How negative are the consequences?**

Think about what is affected when they use the substance. Has their physical appearance, behaviours or relationships changed? Are they able to do their work and/or keep up with their responsibilities?

- **Do they continue using despite negative consequences?**

Think about how they are continuing to use these substances. Do they continue even when they feel sick or start to have health problems? Do they experience more cravings or urges to drink or to use drugs, or do they stop?

- **Do they consume more and more of the substance as time goes on?**

Think about when they are drinking or using substances. Are the amounts getting larger or smaller? Do they try different substances? Are they trying to cope with anxiety or trying to fit in?

## Signs of substance misuse

Following are just a few of the common signs that people with substance misuse can experience. It is not only Autistic people who experience these—everyone who experiences substance misuse may have a variety of different body, doing and thinking signs.

Body signs	Doing signs	Thinking signs
<ul style="list-style-type: none"> <li>• Sleeping too much or too little</li> <li>• Physical appearance changes:               <ul style="list-style-type: none"> <li>→Weight loss or gain</li> <li>→Body shakes and tremors</li> <li>→Bad breath and/or body odour</li> </ul> </li> <li>• Speech changes:               <ul style="list-style-type: none"> <li>→Rapid or rambling speech</li> <li>→May have slurred/slow speech</li> </ul> </li> <li>• Feeling sick when not on substances (stomach aches, headaches)</li> <li>• Low coordination</li> </ul>	<ul style="list-style-type: none"> <li>• Aggressive behaviours</li> <li>• Not meeting responsibilities at home, school or work</li> <li>• Engaging in more dangerous or risky activities:               <ul style="list-style-type: none"> <li>→Stealing items (such as drugs or alcohol)</li> </ul> </li> <li>• Continuously taking the substance even though it creates problems</li> <li>• Being secretive</li> <li>• Never focused</li> </ul>	<ul style="list-style-type: none"> <li>• Feeling confident when using the substance in ways/situations the person typically does not feel confident</li> <li>• Feeling confused about situations or not feeling in control of situations</li> <li>• Feeling irritable more than usual</li> <li>• Losing interest in things and activities once enjoyed</li> <li>• Lack of motivation</li> <li>• High anxiety or paranoid thinking</li> </ul>

### Autistic experiences with substance misuse

“I used alcohol in my teens to cope with sensory overload and social environments. My home life was bleak, and I was not at all understood. To escape this, I would go out and party, but could only do so if I drank, because it dulled my senses a lot. This was my coping mechanism and it worked but was not very healthy and would exhaust me.”

“During my early to mid-20s, I commonly drank alcohol in excess while with peers at nightclubs or parties, not merely to enhance excitement but, rather, to assist in feeling more comfortable and confident approaching women I hoped to flirt with—an area of socializing that did not come naturally to me when sober. Despite feeling much more confident in such situations, there were several instances in which I later regretted the way I had acted as a result of having way too much to drink, which included making a fool of myself in front of my friends, vomiting, or displaying anger toward others. Fortunately, my tendencies of drinking in excess were infrequent, confined to large social gatherings and didn’t lead to an addiction. I later learned to limit my drinking in similar social situations, such as to have a ‘buzz’ but not make a fool of myself, which I now view as a happy medium.”

## Obsessive-compulsive problems

It's common to go and check if the door is locked, or the stove is off, or to worry about getting sick. **Obsessive-compulsive disorder** (OCD) is when these kinds of thoughts and behaviours change in ways that interfere with daily life.<sup>12</sup> Although many behaviours that can be found in OCD, such as anxiety, repetitive behaviours and social problems, are also common in autism, these are not necessarily the same as an OCD.

**Obsessions** are distressing and distracting thoughts or images that repeatedly occur.

**Compulsions** are behaviours or rituals that people feel forced to do repeatedly to stop the obsessive thoughts.

Obsessive-compulsive difficulties feel uncontrollable, unwanted and forced. **Obsessions** are repeated thoughts or images that occur in a person's mind that they can't stop, and most of the time these thoughts are distressing and distracting. **Compulsions** are behaviours or rituals that people feel forced to do again and again to get rid of the obsessive thoughts.

Some Autistic people may have obsessive thinking in ways that can cause distress. They may have difficulty stopping thoughts about social situations—times they have felt shamed, excluded, rejected, treated unjustly or unkindly. For example, even years later, they may be unable to stop thinking about a time someone was late and ruined the evening or put them down for being late for work.

### What are common types of OCD?<sup>13</sup>

- **Checking**

**Compulsion:** the need to check on something (e.g., checking locks, windows, taps or ovens); **Obsession:** to prevent danger (e.g., fire, harm).

- **Contamination**

**Compulsion:** the need to wash, clean or avoid; **Obsession:** worry of being dirty and contaminated or of contracting a contagious virus or disease through, for example, shaking hands, using telephones or using public washrooms.

- **Symmetry and ordering**

**Compulsion:** the need to have everything lined up; **Obsession:** to ensure everything is in the right spot to feel comfortable and sometimes prevent harm. For example, neatening surroundings or aligning items.

- **Ruminations/intrusive thoughts**

**Compulsion:** repetitive thoughts; **Obsession:** thoughts about a subject or question that is aimless, uncontrollable and distressing. For example, having supernatural-themed thoughts.

- **Hoarding**

**Compulsion:** inability to let go of specific possessions; **Obsession:** emotional attachment to an item. For example, a person may hoard newspapers, letters, household supplies or other things that seem to have no personal value to others.

## Signs of OCD<sup>12-13</sup>

Following are just a few of the common signs. Depending on the type of OCD, some or none of the below may apply. It is not only Autistic people who experience these—everyone who experiences OCD may have a variety of different body, doing and thinking signs.

Body signs	Doing signs	Thinking signs
<ul style="list-style-type: none"> <li>• Scars on the face and skin from repetitive body-focused behaviours (nibbling, picking)</li> <li>• Recurring open wounds               <ul style="list-style-type: none"> <li>→Skin is raw or broken from overwashing, picking or scratching</li> <li>→Some areas of the body may be infected</li> </ul> </li> <li>• Noticeable hair loss due to hair pulling (also known as trichotillomania)               <ul style="list-style-type: none"> <li>→Thinned or bald areas on the body</li> <li>→Missing eyelashes or eyebrows</li> </ul> </li> <li>• Hiding scars by putting on makeup and getting tattoos</li> <li>• Damaged nail cuticles from nail biting</li> <li>• Raw or bleeding inner cheeks or lips from lip and cheek biting</li> <li>• When unable to perform the repetitive behaviour, the person feel may feel nauseous, sweaty or shaky, or their heart beats faster</li> </ul>	<ul style="list-style-type: none"> <li>• Checking things like locked doors, appliances and lights over and over</li> <li>• Checking on loved ones over and over to make sure they are safe</li> <li>• Counting, tapping or repeating certain words to lower anxiety</li> <li>• A lot of time spent on washing or cleaning, to a point that it is a problem for the person and/or disturbs their daily life</li> <li>• Avoiding touching objects or others (like shaking hands)</li> <li>• Constant arranging or organizing things</li> <li>• Performing in unwanted rituals</li> <li>• Keeping items or finding it hard to throw away items that may not have a special meaning</li> <li>• Asking the same questions over and over</li> <li>• Needing to record obsessive activities</li> </ul>	<ul style="list-style-type: none"> <li>• Fearful of getting sick, getting in contact with germs</li> <li>• Feeling afraid of losing control and hurting oneself or others</li> <li>• Unwanted constant thoughts of making sure everything is perfect or “just right”</li> <li>• Feeling like they don’t have everything they need</li> <li>• Having disturbing or inappropriate thoughts that can’t seem to stop (also known as “intrusive thoughts”)</li> <li>• Believing in supernatural influence on what happens in daily life (superstitions) to maintain good luck or avoid bad luck—unrelated to spiritual, cultural beliefs</li> <li>• Thinking of intrusive scenarios in one’s mind that may never happen</li> </ul>

## Autistic experiences with OCD

“I was diagnosed with OCD at the age of 12. Intrusive thoughts and scenarios kept going through my head. I am a checker, so checking a certain area thoroughly might be enough or it might not. I also take medication for OCD. Alongside autism, OCD has been significant in shaping my life as well as fuelling my perfectionist behaviour with my military models and neighbourhood-watch operations.”

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“For me, my OCD really picks up when I’m anxious, and so it becomes a sort of barometer for my emotional climate. If my OCD is picking up or I’m having more trouble ignoring it, then I know something’s up and my anxiety is on the rise. It’s tiring. Some ticks are harmless, and I allow them—I walk around the manholes in our street in a certain way and certain order, and that I let slide. But there’s other ticks that I need to stop cold, and that hurts.”

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“It can be hard to differentiate between autism and OCD sometimes—similar to how autism and ADHD can be hard to differentiate. Certainly, there is a lot of overlap all around. For me, the difference between OCD and autism is that with OCD, I’m always asking ‘What if?’ If I don’t check each question I fill out in an exam or a form three times, what if I get it wrong and something bad happens? If I don’t wash my hands for a certain amount of time, what if there are still pathogens on my hands and I get sick? Catastrophizing plays a big role.

“In contrast, things that are anxiety-provoking to my Autistic mind-body are distressing in and of themselves and often interact with my disability and the environment to create barriers. For example, rushed transitions and unexpected surprises are overwhelming, period. Same goes for loud noises and bright lights. What I get is an immediate visceral reaction—literal physical pain. Things that are comforting to my Autistic mind-body, such as eating familiar foods or carrying stim toys and comfort items around, are soothing on their own in their repetition and familiarity.

“To me, autism is a much more embodied experience. It is a part of my mind and body, a part of me. OCD only happened to me later. This is why I say I am Autistic, but I have OCD.”

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“I kept pillow cases, I kept torn pieces of wallpaper, I kept an old sundress my mom used to wear—because they were a part of my life, and throwing them away, discarding them, was like taking a part of my home, my life, and just throwing it out, like it meant nothing. I hate change. I hate the word ‘goodbye.’ I hate loss. Even the wallpaper—because it was there through all our Christmases, all our birthdays and rainy days and times together. So, I kept it until I was ready to throw it away.”

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“I’ve had trichotillomania since I was about nine years old. I’ve come to a place of acceptance about it now, but it’s greatly impacted my life, my confidence and my relationships in the past. I’ve had to shave my head and wear wigs in the past. Trich is also a manual and oral stim for me. Despite countless attempts to curb this behaviour, I’ve been unsuccessful, which is why I now live in acceptance of it. The guilt and shame associated with it was just too much to bear, especially since it alters my appearance so drastically and I’m already at risk for bullying and ostracization.”

## Psychosis

**Psychosis** is a state where a person experiences hallucination and/or delusions.

People experiencing **hallucinations** may hear, see, smell or feel things that are not real or present, such as<sup>14</sup>:

- hearing voices
- strange sensations or feelings
- seeing objects, people or creatures that are not there.

**Delusions** are strong beliefs that may not be true or unreasonable to others. During delusions, people might have repeated unwanted thoughts and feelings that are not based in reality, such as<sup>14</sup>:

- believing outside forces control their thoughts, feelings and behaviours
- believing that simple comments, events or objects have personal meaning
- thinking they have powers, are on a special mission or that they are the chosen one or God.

Most of these experiences can be frightening and confusing for the person experiencing them. Episodes of psychosis may occur because the person is living with a mental health problem such as schizophrenia, bipolar disorder or severe depression. Certain substances (e.g., drugs) can also bring about hallucinations and delusions.

Psychosis makes it difficult for a person to take care of themselves and others (e.g., having a job, keeping family relationships and friendships). For example, people with **schizophrenia** will experience hallucinations and delusions, have fast and disorganized speech and can have difficulty coordinating their motor movements. They also can experience social withdrawal, have a harder time with self-care, have sleep problems or have muted emotional responses (sometimes called the “negative traits”).

Most Autistic people will not experience periods of psychosis, though it can occur more frequently than for non-Autistic people. It is relatively rare compared to the other conditions we describe in this section.<sup>15</sup> If Autistic people do experience periods of psychosis, PTSD, C-PTSD or dissociative disorders may be contributing factors. Noticing periods of psychosis or schizophrenia in Autistic people can be difficult and can be missed because people may misinterpret the signs of psychosis as part of a person’s autism. This is why knowing a person’s usual self is important.

## Signs of psychosis<sup>14-15</sup>

Following are just a few of the common signs that people can experience. Depending on the type of psychosis, some or none of the below may apply. It is not only Autistic people who experience these — everyone who experiences psychosis may have a variety of different body, doing and thinking signs.

**Psychosis** is when a person experiences:

- **hallucinations** (seeing, hearing, smelling, feeling things that are not there) and/or
- **delusions** (believing in things that are not consistent with the person’s values and that may not be true or reasonable to others).

Psychosis can happen in people with schizophrenia, bipolar disorder and some cases of depression.

Body signs	Doing Signs	Thinking Signs
<ul style="list-style-type: none"> <li>• Decreased self-care or personal hygiene</li> <li>• Sleep problems</li> <li>• May appear to be in a trance-like state (catatonic, motionless or in a daze)</li> <li>• Overactive and uncoordinated movements</li> <li>• Verbalizations do not make sense (slurred speech, irrational sentences)</li> </ul>	<ul style="list-style-type: none"> <li>• Wanting to be alone</li> <li>• Seemingly agitated</li> <li>• Disengaged with others</li> <li>• Talking to self or yelling at voices</li> <li>• Rigid behaviours</li> <li>• May be aggressive</li> <li>• Impulsive thoughts and decisions</li> <li>• Setting unrealistic goals</li> <li>• Disorganized and dangerous behaviours</li> <li>• Engaging in dangerous activities</li> <li>• Unaware of their own surroundings</li> </ul>	<ul style="list-style-type: none"> <li>• Experiencing hallucinations or delusions</li> <li>• Being suspicious or having feelings of unease with others</li> <li>• High anxiety about people and the world around them</li> <li>• Having very strong and inappropriate emotions, or having numbed emotions</li> <li>• Having trouble thinking clearly or concentrating</li> <li>• Periods of depression</li> <li>• Disinterested in things or people</li> <li>• Elevated moods, or rapid changes in mood</li> </ul>

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