

Navigating Crises, Emergencies and Pandemics

Snapshot

- Autistic people are at an increased risk of mental health problems, self-injury and suicide.
- Crisis, emergencies and times of uncertainty are experienced differently by each person, and the mental health effects of these events can be long-lasting.
- During a crisis, it is important to ask, “Whose crisis is it?”
- Having a plan of action for times of crisis and uncertainty may help to reduce anxiety associated with the event.
- Creating Mental Health Safety Plans and Crisis Cards can help Autistic people during a crisis.

Content warning: Parts of this section contain detailed discussion about crisis, suicide, emergencies and pandemics, including triggers and symptoms. Reading about these things could be triggering for some people.

Autistic people are at an increased risk of experiencing a mental health crisis. This is influenced by social, psychological and biological factors (see **Section 5**).

Following are some things that could play a part in complicating mental health crisis and which can increase the likelihood of traumatic outcomes:

- Mental health professionals may not be sufficiently trained in understanding autism, which can lead to experiences with services that are not able to adapt support to Autistic people.
- In many places, there are a lack of appropriate services and supports available for Autistic adults, which can make accessing help in a timely manner very difficult.

- There is a lack of appropriate validated assessments to identify mental health problems, such as depression and suicidality in Autistic adults.
- The emergency room department can be a triggering environment for Autistic people who have sensory sensitivities to bright lights, high-pitched sounds, constant noise and/or touch during examination. Additionally, insufficient time to process the information provided by health care providers can place added stress.
- Due to social-communication differences, non-Autistic people may have difficulty understanding the concerns expressed by Autistic adults.

Without practical crisis plans and supports, Autistic adults may develop even more complex support needs. This can negatively affect Autistic adults' experiences with daily challenges and may increase the intensity of the crisis and the number of supports they need.

Understanding crises

Crisis

The term “**crisis**” may mean different things to different people and it can depend on who is experiencing it, how they understand the causes of it, their environments and other circumstances. That is why it is said to be subjective. A crisis is when a person experiences a disruptive event or situation with a level of difficulty that goes beyond their current resources or coping mechanisms, and there is distress. Crisis makes doing everyday activities even more challenging. A crisis may occur with little or no warning.

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Crisis looks like a drastic change in behaviour that is alarming to the individual or at least for the person who is seeing it in someone else (e.g., someone suddenly becoming very withdrawn or springing into distressing actions such as wanting to run from the setting they are in while still angry or upset). The spectrum of crisis reactions can range from becoming withdrawn and wanting to leave the situation, to wanting to act out and becoming physical (e.g., punching an object/a person).

In **Section 6**, this guide suggests using the Brief Distress Scale activity to understand whether a person is in crisis and whether action is needed. This activity can also be used to check when distress starts to become a crisis.

Mental health crisis

The term “**mental health crisis**” is also known as a psychiatric emergency. According to the American Psychiatric Association, a mental health crisis has two key factors:

1. A critical mental health event that requires immediate intervention.
2. The lack of perceived or available resources to manage the event.

Sometimes crises happen suddenly. An event may occur that triggers a person beyond their usual coping, and they are at such a point of distress that they are in an emergency situation. Other times, issues can unfold slowly and may build up to a point where the person feels that they cannot ignore it or take it anymore. Sometimes:

- A sudden change in daily routine triggers a crisis that escalates into an emergency.
- There is nothing that can be done to prevent a crisis.
- Other people can prevent or trigger a crisis.

The perception of a situation may vary; one person may think that a situation is a crisis that needs immediate action, while someone else may not. There can be times that an Autistic person may feel they are in crisis but that those around them, like professionals or family members, don't see it. Other times, a mental health care provider or family member may feel that there is a crisis, while an Autistic person is not as concerned.

In these situations, it is important to ask, “**Whose crisis is it?**” The answer will help with understanding who is asking for support: the person, their family member, other caregivers or all of them?

Outside help may be needed. This can come from the person's doctor or therapist, a mobile crisis service or crisis line, or other emergency supports.

During a crisis

When an Autistic person experiences a crisis, people should:

- try to be calm and supportive
- keep verbal communication to a minimum
- ask if they wish to talk to their support network and offer to call a contact for them

- if they have a Mental Health Safety Plan (see below), offer to contact a person on this plan, like a doctor, support worker, case manager or whoever else has been identified.

Following through on these suggestions may help to prevent a crisis from becoming an emergency. However, sometimes an emergency cannot be avoided.

Autistic experiences with crisis

“When experiencing a crisis, I like to go to a private space and be able to write out what I’m feeling. That has always helped me when negative feelings are outweighing positive feelings in the moment, and I have mentioned earlier in my personal experience for the guide that living in this time of pandemic has shown me how cathartic concrete writing can be for me.”

“When I’ve been extremely distressed (this has been rare), I would get extremely withdrawn, want to flee the scene and feel ashamed that I didn’t pick up the warning signs leading to the situation. One example was when I received unwanted attention at a party I was at during the beginning of this year.”

“A crisis looks like I am inert. I often cannot move and may need physical prompting to do so. I am overwhelmed by simple, ordinary demands and move very, very slowly. Negative thoughts take over, and executive skills fall apart. Anything I do takes several times longer than it should, if I can attempt it at all. I do try, because I want to feel better. When experiencing a crisis, I want people to be mindful of my dignity first and foremost. I am a private person, and to cry in front of people is mortifying for me. I do not want people to overreact. I do not want anyone to touch me. I cannot hug anyone when I am anxious, so in crisis it is not an option. Simple, directive statements telling me/reminding me what I can do to feel better help. For example, ‘Let’s go for a walk together,’ ‘Let’s go to a quieter room’ and ‘I am here when you want to talk.’”

“The primary issue is lack of social connections. When my loneliness, and the depression and anxiety that come from that, is sufficiently bad, then I might be in crisis. A necessary, and often absent, support need is support from friends. I tend to be socially isolated because people keep me at arm’s length . . . As a result, I occasionally become preoccupied with thoughts of suicide and get so anxious and depressed that it is very difficult, if not impossible, to take care of my daily tasks or responsibilities.”

“A crisis for me happens when there are too many challenges for me to face, both in my personal life and my environment, and too much is expected of me. I am overworked and bombarded with information and stress. There is so much that is dependent on me functioning and fixing my problems that I reach an escalated state where I can’t turn off my brain or process information. I can’t fix or problem-solve the challenges that I am facing because I am completely overwhelmed by the pressure and outside stimulus.”

Emergency

A mental health emergency is a situation that involves an immediate danger that a person will harm either themselves or someone else.

Examples of emergencies include:

- threats of suicide
- threats of physical violence
- extremely impaired judgment
- inability to care for oneself (e.g., eating, grooming)
- serious physical injury or illness.

Individuals seeking emergency care services can face many challenges. Possible experiences include decreased ability or complete inability to communicate, sensory sensitivity related to the hospital setting, and difficulties with high-intensity situations and environments. Other experiences include inappropriate care, such as long waits for help, restraints, staff showing insufficient knowledge of autism and the needs of the Autistic person being ignored. These are some of the reasons why many Autistic people may hesitate to contact 9-1-1 during their crisis.

If a crisis becomes an emergency

If a person threatens to harm themselves or others, it is important to try to de-escalate the situation. Below are verbal and non-verbal behaviours that can be used to help.

Behaviours that can be useful during a crisis	
Verbal	<ul style="list-style-type: none"> • Give your undivided attention – Ensure that the person feels validated and important by paying attention to them. Do not passively listen, really pay attention. Try to understand what they are experiencing. • Be non-judgmental – Be empathic and do not criticize a person’s actions, reasons or how they respond to questions. • Focus on feelings – Allow the person to express their feelings by creating a safe space for them to share. Example of a probing statement: “That must feel pretty scary/hard.” • Allow silence – Avoid the need to fill in silence in crisis situations. If a person doesn’t respond at once, give them time to process the question or think about their answers. Perhaps they just need a person to be with them. • Ask what they need – Ask the person in crisis what they need to make things better in the moment. When they do not know, they may know what would not be helpful, so you can ask that, too.
Non-verbal	<ul style="list-style-type: none"> • Respect personal space – Provide the space people need to feel comfortable; this can vary from person to person. It is important to respect a person’s need for personal space, especially in a crisis. Do not touch them, but if you have to, always ask consent. • Be aware of your body language – It is important to be aware of your posture, facial expressions or gestures that may appear defensive or threatening (e.g., shaking a finger, putting hands on hips, rolling eyes).

Supporting Autistic people in crisis

Being prepared can help prevent a situation from developing into a crisis and ease a person's pain and anxiety if a crisis does occur. Having a support team in place is good.

This support team can involve any services and trusted people that are identified as potentially helpful, including a person from a social network. This could be a family member or a friend. Have their phone numbers or other contact information on hand, and make sure that they have agreed to be part of the team and they

understand in advance the helpful ways to respond in terms of their actions and demeanour. There are many ways to prepare for a crisis, such as developing a **Mental Health Safety Plan** or preparing **Crisis Cards**.

Creating a Mental Health Safety Plan

A Mental Health Safety Plan can be helpful in times of crisis. It's a tool that can be used to promote safe practices during a crisis and help the person experiencing the crisis to better cope.

The following guidelines, adapted from Dr. Cassidy, University of Nottingham, can help create an action plan tailored to a person's needs in a crisis. This plan can be completed alone or with help from a support team.

Guidelines to filling out a Mental Health Safety Plan	
<p>Step 1 Know the warning signs of a crisis</p>	<ul style="list-style-type: none"> • What are thoughts, images, moods, situations or behaviours that might show that a crisis might be developing or that you're not doing so well? • Try to list at least one.
<p>Step 2 Identify activities you can do by yourself to help take your mind off things</p>	<ul style="list-style-type: none"> • What are three activities you can do by yourself to try to take your mind off things without talking to someone else? • If you can't list three, start with one.
<p>Step 3 Think of who you can reach out to or places you can go to help take your mind off things</p>	<ul style="list-style-type: none"> • Try to identify at least two people you can call or reach out to, or two places you can go, without yet asking for help. This is to try to distract yourself from the crisis growing bigger and trying to decrease it. • Write down their names, their relationship to you, their phone number and the address of a safe place, so that you always have it handy.
<p>Step 4 List, in order, the names and numbers of who you can contact in a crisis to ask for help</p>	<ul style="list-style-type: none"> • Who's the first person you would contact who can help to get you through a crisis? • Who else can you think of? Write their number down in case you need to contact them. • If you can't think of anyone, list any number or contact information you may have from an advocacy or peer support group. • Call a suicide prevention and support line. In Canada, you can call 1-833456-4566 for Crisis Services Canada or you can text the Crisis Text Line "HOME" to 686868 any time for any type of crisis. They are available 24/7. • As a last resort, dial 9-1-1 or your emergency line.

<p style="text-align: center;">Step 5</p> <p style="text-align: center;">Identify the things that supportive people can do to help you stay safe</p>	<ul style="list-style-type: none"> • What can your support team do to help you stay safe? <ul style="list-style-type: none"> · Are there any weapons in the home? Can they lock them up? What about things like rope? Can they help you get rid of it? · Medicine—can they lock it up or can someone be in charge of giving it to you every day?
<p style="text-align: center;">Step 6</p> <p style="text-align: center;">Identify how others can support you personally when you are in a crisis</p>	<ul style="list-style-type: none"> • What are some ways that others can help you while you are in a crisis? • How do you want others to communicate with you? (e.g., speaking softly, visual supports, etc.) • What will trigger you more (e.g., loud noises, being touched)? • Who do you want them to contact?

The following is a sample sheet that can be used to create a personal Mental Health Safety Plan, considering these 6 steps. Consider how the crisis plan can be shared with other people (family members, friends, emergency or hospital staff, etc.).

(Insert Name) _____'s Mental Health Safety Plan^a

Warning signs

1. _____

2. _____

3. _____

Activities I can do by myself to try and take my mind off things

1. _____

2. _____

3. _____

People and places to help take my mind off thing

People I can go to:

1. Name: _____
Relationship: _____
Number: _____

2. Name: _____
Relationship: _____
Number: _____

Places I can go:

1. _____
2. _____
3. _____

People I can contact for help when I'm in a crisis

Name #1: _____
Relationship #1: _____
Phone Number #1: _____

Name #2: _____
Relationship #2: _____
Phone Number #2: _____

Name #3: _____
Relationship #3: _____
Phone Number #3: _____

Ways that supportive people can help me stay safe

1. _____

2. _____

3. _____

How can other people help support me?

1. _____

2. _____

3. _____

^a The original version of the Autism Adapted Safety Plan was developed by Dr. Sarah Cassidy, University of Nottingham, UK. It is available free to download at <https://sites.google.com/view/mentalhealthinautism/resources/safety-plan>.

Crisis Cards

Some Autistic people and their family members have found it very helpful to write important information on a card or a piece of paper folded small enough to be carried with them wherever they go. The paper may be placed in a visible part of the person's wallet, or they can take photos of it on their phone.

A Crisis Card usually has important information for others (e.g., friends, health care workers, strangers) to be aware of if the Autistic person experiences a mental health crisis while away from home. The card can have information such as:

- important phone numbers: who to call in a crisis or an emergency, including who to call first and who to call as a back-up
- their mental health care provider
- their family doctor
- the centre/agency at which they currently receive or have previously received inpatient or outpatient care
- a list of current medications, the proper dosage for each and when they are to be taken (it may be helpful to include the name and phone number of the pharmacy where the prescriptions are usually filled)
- a list of medications to which they are allergic
- any medications used in the past that did not work or that were not taken due to side-effects (list such medications in one column and list side-effects in a second column)
- tips for effectively communicating with the person and working with them when they are in crisis (communication cards; topics of interest to them for either engagement or distraction; comforting foods; self-calming activities like stimming, music or fidget toys).

MyHealth Passport, developed by the Good 2 Go transition program at the Hospital for Sick Children, is an online interactive tool that organizes information into a wallet-sized card that can be downloaded and printed. Different types of passports can be created, such as one for mental health or autism.

There are other tools available online, such as the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit. AASPIRE is a community of academic and Autistic people who conduct research that aims to improve the lives of Autistic people. This Healthcare toolkit has forms and worksheets that may be helpful as a person navigates through the health care system, such as a Symptoms Worksheet and an Autism Healthcare Accommodations Tool.

Suicide

One of the most terrifying aspects of a serious mental health episode can be hearing a person talk about suicide. Any talk, even joking, about suicide *must* be taken seriously.

Suicidal thinking or attempts typically occur during a severe mental health episode when the person feels helpless and hopeless and is in a state of despair. Although the feelings are often temporary, at the time the person may not believe that the feelings of hopelessness and helplessness will pass. It can be helpful to acknowledge a person's feelings while offering to help them find other solutions.

Lack of support for Autistic adults is related to an increased risk of depression and suicidality.¹ Autistic adults also report having more unmet needs than non-Autistic adults,¹ and Autistic people face challenges in accessing appropriate mental health supports, especially when in crisis.² Although they face higher risk of suicidality, they are less likely to access mental health supports.

Warning signs of suicide

There are several warning signs that a person is considering suicide. They may:

- discuss suicide and what it would be like to have things end
- be concerned with providing for children, other family members or pets
- give away possessions unexpectedly
- prefer to stay home and isolate more than usual
- express feelings of worthlessness, such as “I’m no good to anybody”
- feel hopeless about the future, reflected in comments such as “What’s the use?” that are expressed repeatedly
- talk about voices that tell them to do something dangerous.

What to do if you find someone during or after a suicide attempt

- Dial 9-1-1 or your emergency line immediately (the number varies from place to place).
- If you know first aid and are comfortable providing it, administer it immediately.
- Get someone to go with them to the hospital or to stay with you at home.
- Do not try to handle the emergency alone: contact a support group to help you with your immediate reactions and long-term feelings.

The impact of a pandemic on Autistic adults

While this guide was being written, the COVID-19 pandemic happened. As a result, society and how people live their lives were changed abruptly. The uncertainty, fear and changes were felt worldwide, and the pandemic experience was wide-ranging, in some cases isolating people and causing a disruption to their regular routines. Autistic people were affected physically, economically, socially and psychologically.

Physical

There are some Autistic people who have physical disabilities and chronic illnesses and medical conditions. Even in the best of times, Autistic people often struggle to access appropriate health care. All these factors may increase risk of illness if the Autistic person gets COVID-19. Another consequence of the pandemic is that health care has been harder to access and some people are frightened to use health care when needed because of fears of getting COVID-19; this means that health conditions can get worse or remain untreated.

Economical

Many Autistic people are particularly vulnerable to the pandemic's economic effects, with so many people already experiencing underemployment and unemployment prior to COVID-19. The pandemic puts them at a further disadvantage in society because they may not be able to keep paying for rent or be able to buy food as part of their health.

Social

Some Autistic people may feel more stressed about the changes to their daily routines caused by the pandemic (e.g., work changes or job loss, loss of outside activities such as networking or socializing).

Prior to the pandemic, access to social and formal supports were limited for Autistic people. With the physical distancing measures that have been put in place to reduce the spread of COVID-19, in-person supports are even harder to access. Additionally, information surrounding the pandemic and the related policy and political events not being written in plain language makes it difficult for some Autistic adults to feel well-informed.

Some Autistic people may feel relief from the usual social stressors they would normally face, and which have been removed because of COVID-19, such as in-person social events, school, work and appointments. However, many Autistic adults struggle with new social interaction difficulties directly related to the pandemic, such as being unable to read faces because of face masks and having difficulty with the back-and-forth flow of social interaction during video calls.

Psychological

If an Autistic person was already likely to experience low positive mental health and more likely than the general population to experience crisis, the mental health consequences of a pandemic can be devastating. Autistic people often face loneliness and social isolation, so losing access to their support network during the pandemic could have a serious effect on their overall mental health. Experiencing a pandemic may be associated with anxiety, depression and posttraumatic stress.

Lessons from the COVID-19 pandemic

The effect of the pandemic is likely very significant for many Autistic people. Stress because of unexpected change and uncertainty, high risk of vulnerability, and health problems could all be magnified. It is important to identify the lessons the pandemic has provided for society and use what we've learned to inform future practices.

1. We need to remember that all people are essential, and that the government should not discriminate against Autistic people and disabled people. People can ensure that the suggestions and policies during a pandemic are truly inclusive.
2. We need to create credible resources and tools that are informed by the Autistic community and the disability-rights community, and make sure that we are using a lens of accommodation. Autistic people need to be consulted in the development of pandemic-specific tips and tools offered to the Autistic community, and for adults specifically. For example, autism-tailored information and advice, and tips for accessing existing resources.
3. Autistic people need continued support, whether online or in person. Many Autistic people who did not need regular support before the pandemic report needing it now, but they do not know how to access the right services.³ When offering online support, do not assume that everyone's socioeconomic status, communication, technology access or family are the same. For instance, some Autistic people may not have access to technology or to private space, or they may experience anxiety on voice or video calls. Phone support may be difficult or impossible for some Autistic adults who may want to see the faces of those speaking to help them interpret intent of communication. Offer different, creative and inclusive resources or solutions for those who need more support.
4. It would be positive if, because of the pandemic, people come together and become more accommodating in general. For example, some Autistic people have reported receiving crucial support from within the Autistic community as they share their experiences and resources (e.g., community care).³ Others have reported that the pandemic brought a sense of autism acceptance, and that accommodations that Autistic people have already been asking for are now occurring more broadly, such as being able to access health care virtually or being able to work from home.

Autistic experiences with COVID-19

“I have struggled with the pandemic because the few in-person social interactions with the friends I have in my real life have been stripped from me. At the same time, however, participating in events online has become normalized for all and I am busier than ever. I am able to attend webinars and concerts and educational series that I would have never had access to previously. However, I do struggle with things like arrows on the ground telling you where to go in stores, and distance markers. I really struggle with physical directions even at the best of times, and I often find myself lost and not knowing what to do in situations that would have been easy for me previously. I am also really struggling with people who don’t wear masks and who do not physically distance, and I am genuinely fearful of people who break the rules and put myself and others at risk. As far as my mental health [goes], I have survived by relying on the Autistic community online. In some ways, I feel that I am uniquely suited to enduring a pandemic because I am Autistic and I already had robust Autistic-led support structures available to me, whereas moving primarily online for these supports and interactions is a new experience for others.”

“My experience with COVID-19 has been a difficult but more fortunate one, since I did not lose most of my jobs when mid-March came around. I miss in-person office interactions with the work team and being able to go to places without a face mask. And at the start of the pandemic, I did not feel comfortable to spend Easter with anyone other than my roommate, so I didn’t spend it with my family (an unfortunate first). However, they passed an Easter dinner to me and my roommate at the front of the building we live in, and then the rest of our interactions were behind the front-entrance glass and door as we waved, blew kisses and they put up “We love you” poster signs. However, it has also been a time for reflection and working on my own mental health, so that when all pre-COVID-19 activities such as work parties can be done again, I can approach them with renewed energy and not take them for granted. I’ve maintained my mental health with colouring, leisure writing, walking, at-home exercises and (now that it’s possible) going to the gym (while abiding by COVID-19 protocols).”

“I am struggling through COVID-19. I believe this is primarily because of the pandemic’s impact on others; many of my usual supports are currently overtaxed, and I am having much fewer conversations with friends as a result of their crises. As for my own mental health, I am prioritizing this but am struggling. I am mainly trying to keep up routines and get enough necessities such as food.”

“COVID-19 has been a relief of the crammed schedule, but stressful with lack of social interactions and outings. The new rules and regulations and the federal financial as well as provincial financial situation are worrisome. I worry about family getting sick, including parents that are in the higher risk bracket. I maintain with projects, online presentations and working out, etc.”

“During my experience with the COVID pandemic and lockdown, the hardest part for me is when I’m living with a single parent in my 20s. I did not have a lot of privacy and I was on my social media every day. It was hard for me to get out of that emotional prison. The best way to deal with the situation while the ASD person is in emotional distress: never gaslight someone for giving you discomfort. If both parties are emotionally offended or getting defensive, they would need their own privacy to be left alone, instead of being invaded. Privacy for me was what I needed, and I needed to take myself out of the situation.”

References

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