

What To Do When I Don't Feel Okay: Big Ideas

This guide was written by Ren Koloni, an autistic self-advocate with mental health support needs who has experienced crisis.

Ren is a part of the team at [CommunicationFIRST](#), a partner of The Link Center.

To write this guide, Ren combined their lived experience with existing resources for crisis support.

That means this guide isn't the result of research and shouldn't be taken as medical or legal advice.

For more information on resources for people with I/DD and mental health support needs, connect with The Link Center at thelinkcenter@nasdds.org.

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This guide explains some big ideas about crisis and crisis plans, like:

- [What is a crisis?](#)
- [Why does a crisis happen?](#)
- [What is a crisis plan?](#)
- [What should I think about when I make my crisis plan?](#)
- [Who can help me?](#)
- [What do I do if I don't know anyone who can help me?](#)
- [Other words to know](#)

This guide is made for people who have I/DD **and** mental health support needs.

This guide can help you learn how to stay safe during a crisis.

At the end of the guide, you can look at some different versions of crisis plans.

You can choose a crisis plan that works best for you.

NOTE: We will update this guide as we discover new resources. So, this list doesn't have every resource on it yet. If you have a favorite resource that we missed, email us at thelinkcenter@nasdds.org and tell us about it!

What is a crisis?



Everyone has times in their life when they don't feel okay.

We might feel sad, angry, upset, restless, tired, hopeless, or like everything is just too much.

We might need help from someone else before we feel better.



A **crisis** happens when we are overwhelmed by bad feelings.

In a crisis, we feel so bad that someone might get hurt if we don't get help.

For example:

- You might want to hurt yourself.
- You might wish that you were dead.
- You might want to hurt someone else.
- You might want to stop feeling what you are feeling, no matter what it takes.
- You might not be able to take care of yourself in the ways you usually do.
- You might not be able to control your body in the ways you usually do.



A crisis can be very dangerous.

It is important to get help when you feel like you are having a crisis.

You deserve help, support, and care, no matter how bad you feel.

Why does a crisis happen?



A crisis happens when you can't manage your stress on your own.

A crisis can happen to anybody.

But some people are more likely to have a crisis in their lifetime.



People with mental health support needs might have a crisis because of their mental health condition.

Mental health support needs are things like depression, bipolar disorder, anxiety, schizophrenia, dissociation, or PTSD.

They might also be called **mental illnesses**, or **psychiatric disabilities**.



People with intellectual or developmental disabilities (I/DD) can feel stressed more easily than people who don't have I/DD.

Stress can feel very intense and overwhelming for people with I/DD.

And, sometimes we need things that other people don't. It might be hard for us to get what we need.

Because of this, people with I/DD might be more likely to have a crisis.



Everyone needs things to live, like food, shelter, rest, and support from other people.

If you are disabled, you might need other things, like medicine, assistive technology, and someone who helps take care of you.

If you don't have what you need to live, you are more likely to have a crisis.

What is a crisis plan?



A **crisis plan** is a guide.

It tells you and your supporters what to do when you are having a crisis.



You write a crisis plan when you are feeling okay.

Then, if you have a crisis, you and your supporters can check your crisis plan to figure out what to do next.



When you are in crisis, you might feel too overwhelmed or confused to make choices.

A crisis plan can help you make decisions about your life, even when you are not feeling well enough to make decisions.

A crisis plan can help keep you safe.

A crisis plan can even save your life.



Everyone's plan is different.

A crisis plan is about what will help **you** to feel better and stay safe.



Your crisis plan might talk about things like:

- Medicines that help you
- Ways you can feel safer or more comfortable
- Supporters who can help you
- What kinds of communication tools or supports you might need
- Things that other people should know if they want to help you

What should I think about when I make my crisis plan?



Choose the right crisis plan for you.

There are lots of different crisis plans.

There are some examples at the end of this guide.

You should choose a crisis plan that you feel good about.

Your crisis plan should make sense to you.

You should be able to access, understand, and change your crisis plan, whenever you want to.

Your crisis plan should communicate the things that are important to you.



Know what “crisis” means to you.

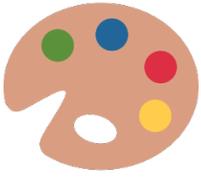
A crisis isn't just feeling suicidal. There are lots of kinds of crises.

Think about what it looks like and feels like when you are having a crisis.

Writing down what having a crisis is like for you can help both you and your supporters know when you need help.

If you know that you might have more than one kind of crisis, you might decide to fill out more than one crisis plan.

For example, you might have a plan for when you have a meltdown, and another plan for when you are having a manic episode.



Communicate what matters to you.

Sometimes, to say what we need to say, we need to get creative.

If there isn't space for something that's important to you, make space!

You don't have to stay inside the lines.

You don't have to answer every question.

You can write in the white space or make a copy to add extra text boxes.

You can even record a video of you explaining your crisis plan.



Include the ways that your disabilities might impact you in a crisis.

Many of us use assistive technology or help from other people in our lives.

During a crisis, we might need different kinds of help.

Think about how your needs might change when you are in a crisis, like:

- The ways that you communicate (speech, AAC, sign, and more)
- The kinds of help that you need with daily activities
- Things that could become emergencies if no one around you knows about them (like your medical conditions, or ways to care for medical equipment)
- Problems you have that get worse when you're under a lot of stress (like stimming that could hurt you, chronic pain, or seizures)



Be prepared, so your next crisis is easier to handle.

Decide where you want to keep your crisis plan so you can find it easily, whenever you need it.

If it would help you, make two versions of your crisis plan: a full version with all the details, and a short version that's easier to understand when you're stressed.

If you like scripts, write some scripts for things that might happen during a crisis, like:

- Asking someone for help when you're starting to feel bad.
- Calling a lifeline.
- Talking to a crisis team if they come to your house.

What else would help you feel ready to deal with a crisis? Write it down in your plan.



Remember, you don't have to do this alone.

Choose who you trust to help you if you have a crisis.

You can ask them to help you write your crisis plan, or just share it when it's done.

Talk to them about when you need them to act, and what you want them to do.

Be honest, even about feelings that might seem scary or sad.

Your supporters want to understand and help.

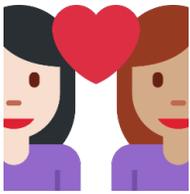
Give them the chance to support you.

Who can help me?



A **supporter** is someone you trust to help you when you are in crisis.

You should feel comfortable and safe with your supporters.



A supporter might be:

- A family member
- A friend
- A partner
- Someone who helps take care of you



A supporter might also be a **professional**.

Professionals are people whose job is to help others, like doctors, therapists, and social workers.



Supporters can help you best when you have a crisis plan.
They can look at a crisis plan and find out what you want to happen.
That way, they don't have to guess, or make a decision instead of you.



You don't have to share your crisis plan with everyone.
You should always be able to choose who gets to see your plan.
But it will help to share with at least one supporter.

What do I do if I don't know anyone who can help me?



A **lifeline** is a place where you can call, text, or type to someone who can help you during a crisis. The people who work at these lifelines can be supporters, too.



The people at lifelines are here to help you.
You can call them if you are having a crisis.
But you can also call them if you are stressed or having a hard time.



The biggest lifeline in the United States is 988.
You can call or text them at 988.
You can chat with them by typing over the Internet.
You can use a TTY service or have a video call in ASL.



Calling 988 is different from calling 911.

For example, 988 tries very hard to avoid the police.

988 will only call emergency services if someone is already hurt and needs emergency help.

You can [click on this link to learn more about the 988 Lifeline.](#)

Other words to know:

Distress

Sadness, upset, or suffering. A big and bad feeling.

Dysregulation

When things don't feel right, and it makes you feel worse and worse. Usually happens because of change, or sensory needs not being met, or when something interrupts your routine.

Ideation

When you are making a plan to hurt yourself or someone else.

Inpatient

A kind of treatment where you go to live somewhere else for a short time to treat a mental health condition.

Outpatient

A kind of treatment where you get treatment for a mental health condition, but still live where you normally live.

Psychiatric

Related to mental health conditions and their treatment.

Self-harm

When you hurt yourself on purpose.

Suicide or suicidal

When you want to die, go away, or not be in this world anymore.

Treatment

A medication or a therapy that is supposed to help you feel better.

Trigger

Something that makes you feel upset or causes a crisis.

Here are some existing crisis plans you may want to use:

1. [My Safety Plan](#)

An online form that makes a PDF with your typed answers.

Accessible? Not screen reader accessible, but it is keyboard accessible.

Helps you share:

- Warning signs that you are feeling not okay
- Coping strategies
- Distractions
- “My supports” (people you feel comfortable talking to about difficult things)
- Professional contacts
- Ways you might self harm (so that these things can be made unavailable). **This section might be triggering for some people**, especially the suggestions they give.

Best used:

- By people who like the idea of being guided by an online tool
- By people who like the idea of getting suggestions for each answer
- As something to pin up and understand at a glance
- As something to carry with you

2. SAMHSA’s one-page “[Safety Plans Work](#)”

A single-page PDF to print out and write on.

Accessible? Not screen reader or keyboard accessible.

Helps you share:

- Warning signs that you are feeling not okay
- Coping strategies
- People or places that help distract you
- People you can ask for help
- Professionals or agencies you can ask for help
- Ways you can make your environment safer

Best used:

- As something to pin up and get information from at a glance
- As a single page to carry with you
- As a summary of other, more detailed crisis plans

3. Mental Health America's [Crisis Plan Worksheet](#)

A three-page PDF to print out and write on.

Accessible? Not screen reader or keyboard accessible.

Helps you share:

- Warning signs
- Triggers for crisis
- Ways to prevent hospitalization
- Emergency contacts
- Lessons from past experiences
- Visitation permissions
- Facility preferences
- Preferences for staff interaction
- Medication preferences
- Treatments you don't consent to
- Other instructions on things that need to be taken care of if you are hospitalized

Best used:

- By people who want to include all the details
- By people who are at risk of being hospitalized
- By people who already have experience with psychiatric treatment, and can be specific about the treatments they do and don't want
- By people who are also interested in filling out a PAD (Psychiatric Advance Directive), which can be legally binding.

A Sample Short Crisis Plan for People with I/DD:

I'm having a crisis right now. What do I do?

My name is:

I live in:

Here's how I describe my disabilities:

My supporters are: (Name, how to reach them, and who they are in your life)

Where can I find my full crisis plan?

Things that help me feel safe:

Things that bring me joy and make life worth living:

How I communicate best when I am distressed:

(Examples: speech, AAC device, pictures, sign language, sounds, a supporter)

Things I need to have with me if I am going to the hospital:

(Examples: assistive tech, AAC device, comfort item, crisis plan, medical information)

I'm having a bad time, or I'm having a crisis. I need to talk to someone.

[Click here to talk to someone at 988.](#) 988 will try not to call the police.

I am hurt or someone else is hurt. We need help from a doctor.

Call 911 so they can send emergency services. 911 might call the police.

My local crisis response team is: (Name, how to reach them, and when to call)