

Depression and Autism: A youth-to-youth guide to coping and getting help

Why we
Created
this
Package

Autism
and
Depression:
What can it
Look Like?

A Note to
Caregivers

Getting Help

Coping
Strategies

A Note
to Mental
Health
Professionals



Acknowledgements

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Some of the members of our co-design team wish to remain anonymous. We sincerely thank the youth and caregiver members of our team for their time, input, and dedication to improving mental health supports for autistic TAY!

We recognize that much work is needed to enhance access to evidence-based mental health care. We hope this package is a helpful first step towards this goal.

Sincerely,
*Stephanie H. Ameis, Corinth E., Megan Henze, Caroline Kassee,
Meng-Chuan Lai, Johanna Lake, Yona Lunsky, Rachael Lyon,
Shannon Pascoe, Shaylene Pind, Connie Putterman, Andrea Shugar,
Margaret Spoelstra, Rianna Sarbajna, Ami Tint*

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Why We Created This

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Since most mental health services weren't designed for autistic people, navigating these systems can be very confusing.

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What are the issues?

It can be hard to navigate the neurotypical world as an autistic youth. Dealing with strong sensory environments and demanding attitudes of others can be hard when you're built differently than everyone else. Sometimes we may have to mask or act in a different way than we feel or are comfortable.

So many of autistic youth's experiences are devalued, invalidated, and gaslit. We are often told our experiences are 'no big deal' and/or you're 'being dramatic'. These words are hurtful and the impact can build up over time.

Many autistic youth develop depression. Mental health concerns can look different in autistic people compared to non-autistic (allistic) people. Because of this, clinicians often miss (and dismiss!) our concerns.



You deserve to get effective mental health support now and we hope the information in these tip sheets can help you.



Why we created this package of tip sheets

The way you experience and process the world is valid. This tip sheet was designed by and for autistic youth, with the support of family carers and clinicians, to help autistic youth talk about their experiences and to help them get the support that they need.

We need to educate others about autism and mental health. These tip sheets can be shared with other people, like our friends, family, or clinicians to educate and advocate for neurodiversity and mental health.

Getting help as soon as possible is more helpful than waiting for a crisis. You don't have to wait until things get really, really bad.

We're all rooting for you!

Points to consider as you read through:

1. This package is geared towards autistic TAY* who can articulate for themselves. However, not everyone can express or communicate their feelings and experiences. Therefore, carers may need to be involved and help by communicating what they see.
2. While many autistic youth may experience symptoms of depression, having these symptoms is not the same as having a clinical diagnosis of depression.
3. This package is not meant to provide a resource for making clinical diagnoses or to direct treatment decisions.

* TAY often refers to youth — 14-25 years of age

Autism and Depression

What Can It Look Like?

Depression is good at making you not feel like ‘you’ anymore and can show up in a lot of different ways.

That is why it is important to know what feels normal to you. It may be helpful to try to notice and record changes from your ‘normal’ (your everyday self) rather than checking all the boxes on a symptom checklist.

See this tool kit to help “Know Your Normal”

<https://www.ambitiousaboutautism.org.uk/what-we-do/connecting-young-people/youth-led-toolkits/know-your-normal>

For some autistic youth, depressive symptoms may feel like they have become your normal.

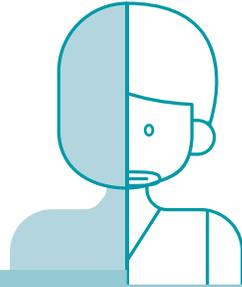
That’s why it’s important to stop and ask:

“Am I happy with my normal? Is this the most healthy version of myself? Have other people noticed changes?”

Keep in mind that autistic people can experience things differently than non-autistic people. Something that may not seem like a big deal to someone else, may hold different meaning and bring about depressive symptoms in an autistic person.

Depressive symptoms also don’t always look the same in autistic people as they do in non-autistic people. Symptoms can change from day to day. You can use this tipsheet to help you, friends, family, and care providers better understand autism and depression.

What to look for:



Little interest or pleasure in doing things:

Things that used to feel fun and that you liked to do no longer interest you (*e.g., you're less enthusiastic about your hobbies or passions*)

Feeling apathetic

Feeling down, depressed or hopeless: Trouble falling asleep or staying asleep, or sleeping too much:

You may also feel numb, sad or lonely
Sleeping more or less than feels normal or healthy for you

Changes in eating patterns or habits:

Poor appetite or overeating

Eating significantly more or less than feels normal or healthy for you

Feeling guilty and you may not understand why:

Feeling bad about yourself, that you're a failure, worthless, or feeling like you're no longer important enough to be cared for by yourself or the people around you

Changes in energy:

Feeling tired, having little energy, overwhelmed

Changes in your usual energy levels but this may be different from day to day

Feeling restless and you cannot stick to one thing at a time (*e.g., you keep switching activities or interests*)

Moving or speaking so slowly that others notice, or restlessness and moving around a lot

**Changes to “thinking speed”
and thinking processes:**

Having a harder time processing information and thinking about things as quickly as you did before (e.g., *brain fog*)

Thinking faster than you can process your thoughts (e.g., *everything feels like it is being sped up*)

Trouble concentrating on things like watching TV, reading, following a conversation, your usual hobbies or passions

Concentrating on different things might be harder than usual, but it could also be easier

**Thoughts about hurting yourself,
death, and/or ending your life:**

All consuming focus or fascination on death

Feeling passively suicidal (e.g., *wishing you did not exist rather than wanting to kill yourself*)

Feeling like it would be easier for other people if you were gone

A lack of intrinsic motivation to stay alive (e.g., *a lack of will to stay alive outside of specific reasons*)

Physical pain:

Experiencing more pain than usual (e.g., *cramping, stomach aches, joint pain, headaches, fatigue, etc.*)

Having a higher pain threshold than usual (e.g., *under reporting pain*)

**Other experiences of depression
reported by autistic youth:**

Sounds, textures, and smells are more bothersome than they used to be

The same noises that used to be “annoying” or “uncomfortable” are now “intolerable”

Feeling burnt out and having lots of meltdowns
Getting frustrated or angry more quickly, yelling

Masking

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What is it?

“Masking to me is putting on a show to better fit in with other people’s social behavior”.

”

Depression can make it difficult to “mask” autistic characteristics. Depression can make it harder to hide stimming or copy what other people are saying or doing to fit in.

Masking often requires a lot of emotional energy and can be exhausting, especially when dealing with depression.

“



My daughter is autistic and lives with depression. Like many parts of her life, her emotions are felt, and expressed, in extremes. Her joy is pure bliss, but her sadness feels catastrophic and unsafe. This can be challenging for caregivers/parents who fear for their child’s safety. We spent many years questioning whether or not she was at risk of harming herself. We needed to learn that she didn’t have the words or the ability to differentiate between elated, happy, fine, ok, sad, grief-stricken or unsafe. This knowledge helped guide us during crises.

”

Getting Help:

“The way my depression manifests makes it easy to hide from others, I spent many years not getting help. But getting help gave me coping skills I didn’t have before. I still struggle to talk about my feelings, but I know when I do they will be heard. If you are struggling with depression you should seek help. It might surprise you.”

Asking for help when you’re experiencing depression can be hard! Here is some info and tips from autistic youth about getting mental health support:

I need help; where can I get it?



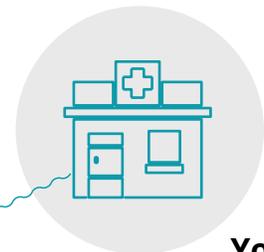
Family doctor (GP) or walk in medical clinic

(<https://www.ontario.ca/page/find-family-doctor-or-nurse-practitioner>)



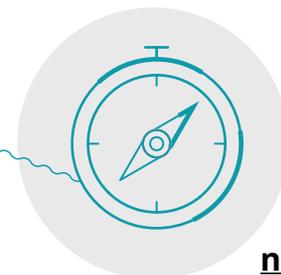
Crisis supports

(<https://helpahead.ca/resources/?services-for&service-type=crisis-line&service-area=&search=#library-form>)



Youth Wellness Hubs

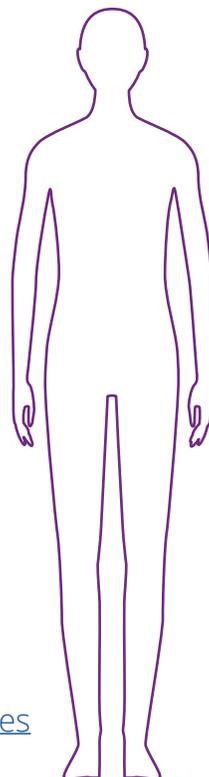
(<https://youthhubs.ca/en/>)

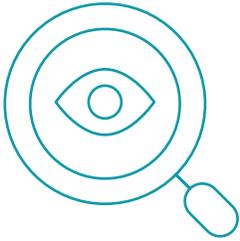


Service navigators

Provide information and make connection with resources mental health service navigation
(<https://sunnybrook.ca/content/?page=family-navigation-project>)

Autism service navigation
(<https://accessoap.ca/>)





Who can you see?

There are many different types of mental health professionals that can support you, including:

Family Doctor (GP) – medical doctor who can diagnose mental health problems and prescribe medication. Sometimes they will refer you to a mental health specialist.

Psychiatrist – medical doctor who specializes in mental health. They can diagnose mental health problems, prescribe medication, and some provide talk therapy.

Psychologist – can diagnose mental health problems and provide talk therapy.

Counsellor, Social Worker, Psychotherapist – can provide talk therapy. There are other helpful options too, including: peer support, life coach, etc.



Remember:

All healthcare providers should treat you with kindness and respect.

Sometimes, autistic youth need to meet with a few mental health professionals before they find a good fit.

You need to feel safe and comfortable working with your mental health professional.

If you do not feel this way, you can ask to see someone else.

Not everyone can express or communicate their feelings and experiences. Caregivers may need to be involved and help by communicating what they see.



Who will be at your appointment?

At the visit, you may meet with a mental health professional and/or a trainee.

It's often helpful to have people who know you well, like your family/friends, come with you to help you describe your experiences and/or help with communicating with the mental health professional.

It's your choice if you would like to have other people involved in your mental health care.



What will a mental health professional do?

Your mental health professional will ask you questions about your thoughts, feelings, and behaviours.

Ask you to complete medical testing, like a physical exam and/or bloodwork. This is done to help understand what may be causing your depressive symptoms and the best way to help you.

May ask you to complete questionnaire(s). This information will help them decide what treatment may be most effective for you.

May ask about whether you feel safe and if you have had any thoughts about harming yourself or others. These are standard questions that are part of the mental health assessment. These questions can help you develop a plan to keep safe during a crisis and identify supports.

Discuss different treatment options with you. This may include talk therapy, peer support groups, and/or medication.

You may hear about a commonly used form of talk therapy called cognitive behavioural therapy (CBT). In CBT, you find out how the way you think about things is impacting how you're feeling.

Tips from Youth for Youth:



Tips to help you prepare:

It can be hard to remember everything you want to tell the mental health professional during the session.

You may find it helpful to bring written notes, audio recordings, or other augmentative and alternative communication (AAC) devices with you.

It can also be helpful to write down ways that you like to communicate with other people and other important information that will allow your mental health professional to best help you.

Some questionnaires ask if you hear noises that other people do not hear and/or if you see things that other people cannot see. These questions are to let the mental health professional know if you are experiencing symptoms of psychosis.

Lots of autistic people notice aspects of their environment that other people do not notice. If you are unsure if you are experiencing psychosis and/or autistic sensory sensitivities, let the mental health professional know that you're unsure so that your experiences can be accurately represented.



Tips that may help during your appointment:

Sometimes youth have a hard time recognizing or explaining what they're feeling. If that happens to you, you can say: "It is hard for me to answer open-ended questions like: 'How are you feeling?' It is easier to answer specific questions like: 'What made you happy this week?'"

Filling out forms might be helpful if it is hard to talk about things face to face. Completing some questionnaires can also be challenging and/or frustrating because experiences do not always fit neatly into the boxes they give you.

If you're having a hard time answering some of the questions, you can leave them blank and write or tell your answer to the mental health professional instead.

When the mental health professional speaks with you about different options, it can be useful to ask them to tell you what the advantages and/or disadvantages of each option are. This can be a helpful strategy to work together to think through what may be the best option for you.

Coping Strategies

Mental Health Tips from youth to youth:

Different strategies will help different people when they are experiencing depression. Here are some ideas of strategies that worked for some autistic youth:



Make sure you're eating and drinking enough. Keep a supply close by of 'safe' food

(e.g., a food that you know you can always eat).



Find creative ways to communicate what you're thinking without words

(e.g., through art, music, dance).



Take time to recharge your social batteries.

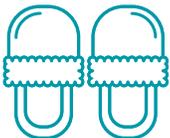
Know what activities are draining and what activities give you energy

(e.g., give yourself time to rest and recover after spending time with other people).



Have a simple goal to accomplish or routine to follow every day

(e.g., put on a clean shirt; make yourself a cup of coffee in the morning).



Spend time in a safe and comfortable environment.

(e.g., somewhere that you can rest, maybe in your room or a space that is quiet and predictable).



Find someone to be your 'safe person'

(e.g., someone you trust and feel comfortable with that you can reach out to for support).

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Having a plant, just a small thing to take care of and that I'm in charge of, helps me to get my butt out of bed in the morning

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A Note to Caregivers

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Do your best to be part of the care team and listen to your loved one. You know your loved one well, allow them to lead as autonomy matters to youth and it is relationship building. Ask for what you need.

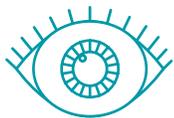
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Coping with depression is difficult for youth, and it's also extremely challenging for other family members too. Here are some tips and resources from other carers of autistic youth experiencing depression who have offered some of their reflections and lessons learned about the process:



Education is key.

Depression can sometimes look like laziness or a lack of motivation. Learning about presentations of depressive symptoms in autism is key to understanding your youth and how to support them.



If you see depressive symptoms, trust your instincts.

You may see signs of depression in your youth that may not be visible or present at the time of the medical appointment. Share this information with the medical professional.



Establish trust and communication.

Have conversations with your youth so you know what they feel comfortable sharing with others. It is important to respect their privacy. Consider letting youth know that you may need to share private information when it relates to their safety.



It's not their fault. It's not your fault. It's not personal.

Recognize that depression may be expressed as hostility, rejection, and irritability.



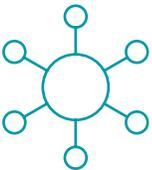
Journeying together: There will be much learning over time.

You and your family will learn new coping skills. Not every method or technique will be well suited for you or your loved one.



Self care matters.

Be kind to yourself and accept that you are going to make mistakes. Make sure to take care of your own needs, including time for activities that bring you joy.



You're not alone.

Reaching out and connecting with other caregivers can bring comfort and much needed support.



Take care and be kind to you.
Ask for help.
You are not alone.



Some helpful places to start are:

Mental Health Literacy Guide for Autism:

<https://www.yorku.ca/health/lab/ddmh/am-help/>

This guide was co-created with Autistic adults and family members from across Canada. The goal for this guide is to provide knowledge about the different factors that can impact Autistic mental health. Section 9 of the guide was created specifically for family carers.

The Family Care Centre by Children’s Mental Health Ontario and Parents for Children’s Mental Health:

<https://www.family.cmho.org/>

This is a network of resources focused on supporting the caregivers of youth with mental illnesses. The website provides a series of tip sheets that address a range of topics including, ‘recognizing symptoms in youth’ and ‘managing a crisis’. Guidance on emotional management, counseling and peer support for caregivers is also provided.

See “Parenting Survival Guide; under Resources” and chapter information under “peer support”.

The Ontario Caregiver Organization:

<https://ontariocaregiver.ca/>

This is an easy to navigate e-library of resources that are tailored to different demographics of caregivers. Support for caregivers includes one-to-one counseling support, access to mental health helplines, information about caregiving services and links to financial support for caregivers.

See “Find support” for more direct support resources.

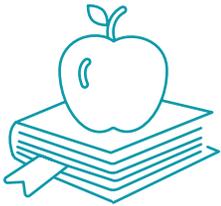
The Family Connections Program overseen by The Sashbear Foundation:

<https://sashbear.org/en/family-connections/family-connections-2>

The family connections programme is a group-based training programme that aims to provide education and develop skills of those who are a loved-one or caregiver of someone with mental illness.

The page includes links to the online webinar sessions and an overview of the program.

A Note to Mental Health Professionals: What clinicians need to know

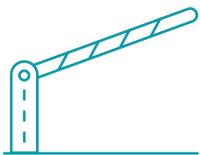


Autistic youth, used here to refer to young people between the ages of ~14-25, are at increased risk for having a number of co-occurring mental health conditions.

1. Rates of depression, bipolar disorder and psychosis spectrum disorders which tend to have their onset in adolescence and young adulthood, are increased among autistic youth.

Depression is one of the most common co-occurring mental health conditions affecting autistic youth. It occurs in ~11% of autistic people vs. ~5% of non-autistic people.

2. In autistic individuals, depression increases with age and is more common in individuals assigned female at birth.
3. Suicidal thoughts and behaviours are more common in autistic youth than other people. Assessing risk and developing safety plans is really important.



Autistic youth often encounter barriers to accessing mental health care.

What are the barriers?

- Some mental health services exclude people with an autism diagnosis
- Some mental health clinicians do not have enough knowledge or experience supporting autistic youth
- It can be hard for autistic youth and their families to navigate our fragmented mental health system

Tip for diagnosing depression in autism: Clarifying current depression symptoms and impairment from longstanding difficulties is challenging. Try to disentangle recent changes in sleep and thought patterns from those that are longstanding. This can help to clarify whether symptoms represent a shift from ‘the norm or baseline’ for an individual and may be part of a co-occurring mental health condition, like depression

Tips to improve assessment and recognize depression in autistic youth:



Mental Health Appointments

Appointments at doctor's offices or other mental health settings can be draining, feel unsafe or uncomfortable for autistic youth. Allow for modifications to tailor the assessment format to the youth you are assessing.

- Ask about preferences for appointments and offer choice (e.g., virtual, in person, phone appt).
- Explore how different modalities may facilitate communication/response to questions (e.g., camera on/off, using chat function/emojis).



Depression can be difficult to spot in autistic youth

In addition to asking about changes in mood (e.g., increased sad mood or irritability), look for these indicators that a mental health condition may be present and contributing to impairment:

- Changes in the level of enjoyment and/or time spent on regular interests/activities (e.g., withdrawal of engagement in usual social/recreational activities).
- Changes from usual routine (e.g., sleep, eating, daily functions and routine activities).
- Uncharacteristic responses or changes in behaviour (e.g., change in irritability, aggression).



It can be challenging for autistic youth to express their emotions

- Additional support or explanations may be needed to help youth respond to questions as they relate to their unique situation.
- Try, where possible, to get input from family or others close to an individual seeking help.
- Questionnaires that measure symptoms of depression can be helpful (see: <https://cundilldepressioncaretool.camh.ca>).
- Note: usual clinical cut-offs on these questionnaires are not validated to measure depression in autistic youth. However, scores can be used descriptively to complement other information collected and track symptoms over time.

Tips to guide treatment for depression in autistic youth:

There are very few studies that focus specifically on assessment/treatment of depression in autistic youth. The current guidance is to provide care that is in line with best practices for youth depression.



A note on safety

Recent evidence indicates the risk of suicide is increased in autistic youth².

- Assess for risk of suicide or harm to self/others.
<https://www.nimh.nih.gov/research/research-conducted-at-nimh/asq-toolkit-materials>
- Prepare for mental health crises.
- A Mental Health Safety Plan can promote safe practices and may prevent emergencies.
https://www.yorku.ca/health/lab/ddmh/wp-content/uploads/sites/407/2021/04/Mental-Health-Literacy-Guide-for-Autism_Section-8.pdf



A note on talk therapy

Talk therapies for depression have not been well studied in autistic youth, though similar therapies have evidence for treatment of anxiety in autism. Modifications that tailor the approach to the individual may improve engagement and enhance uptake of skills. Some modifications that may be helpful:

- Make abstract concepts more concrete.
- Use worksheets, visuals and repeat concepts.
- Incorporate special interests/talents into therapy.
- Extend total number of sessions and/or consider reducing session length to make therapy more comfortable, provide more time to practice and identify helpful strategies.
- If a youth tends to get stuck on certain topics, distraction may be a helpful strategy as opposed to coming up with ways to challenge a maladaptive thought pattern.
- Engage family or a close contact, if possible and comfortable, to help with translating and applying skills learned to daily situations.



A note on medications

- Autistic youth may be more likely to experience side effects when treated with antidepressant medications (*e.g., agitation, hyperactivity*).
- Medications (*e.g., SSRIs*) for moderate-severe depression symptoms can be started low (*e.g. half the regular starting dose*) and increased slowly to optimize tolerability (*e.g., over 2 weeks rather than every 7 days*).

Advocate for and link to autism-friendly supports for engagement/ re-engagement in school, job, recreational activities:

The youth/young adult developmental period is a life-stage associated with higher educational attainment, relationship transitions, and first employment. This transitional period often coincides with the loss of easily available daily structured activity and school-based supports following high school.

Recent evidence suggests depressive symptoms may be higher in autistic individuals not engaged in any activity (*e.g., including school/class attendance, job participation – working, volunteering, recreational activities with others*) compared to those engaged in an activity.

Point to resources that align with an individual's interests and strengths and don't add undue stress.



Resources

To access an online tool for primary care providers and frontline clinicians on evidence-based assessment & management of youth depression:
<https://cundilldepressioncaretool.camh.ca/>

For more youth depression videos and tools search CAMH Cundill Centre for Child and Youth Depression:
<https://www.camh.ca/en/science-and-research/institutes-and-centres/cundill-centre-for-child-and-youth-depression>

For more tips on communicating with youth about their mental health, see the 'Getting Help' tip sheet

For more information on depression in autism:
<https://www.spectrumnews.org/news/analysis-pins-down-prevalence-of-mental-health-conditions-in-autism/>

<https://www.spectrumnews.org/features/deep-dive/the-deep-emotional-ties-between-depression-and-autism/>



For more information related to to Autistic mental health:

See: Autism Mental Health Literacy Project
(AM-HeLP <https://www.yorku.ca/health/lab/ddmh/am-help/>)



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