

# Autistic Mental Health and Formal Supports

## Snapshot

- This section gives brief information about where formal supports can be accessed and what they look like.
- There are different types of supports for Autistic mental health, including but not limited to psychosocial (supports involving others) and medication.
- Mental health supports can be found in different systems of care, such as agencies and hospitals, or from professionals (e.g., psychologists, social workers or psychiatrists).
- There are many types of formal supports, and understanding some of the differences can make it easier to know which support a person may find helpful.
- Medication can be helpful, but it is important to understand the potential side-effects of a medication when making a decision.

Autistic people do better when support is coordinated. This means that everyone working with the Autistic person knows the plan and has a part in it. Instead of getting services separately for each type of challenge, the different types of supports and services work together. If challenges are addressed in this way, people are more likely to experience positive mental health. As mentioned throughout this guide, Autistic people who have mental health challenges are some of the most vulnerable people in society and in our health care system. For many, getting the right supports and services for their individual needs is a long and complex process.

This section briefly talks about where an Autistic person can receive formal supports (these are external supports) and what those supports may look like.

It is important to note that there are people who will not feel comfortable with receiving mental health supports because of past experiences with supports that were dismissive, discriminatory or abusive. In addition, not everyone will be comfortable with, or benefit from, psychosocial supports or medication. Some people feel may want support or feel more comfortable talking to close friends or family members. Financially, some Autistic people who do not receive supports from publicly funded agencies or insurance, or who lack disability welfare, may not be able to afford or access services they need.

## Where to go for support?

Autistic advocacy groups may be a good place to start. Those who lead these groups will have insight into the policies of health care and can provide Autistic people with advice or checklists to consider when looking for supports.

While each province and territory in Canada has a different health care and mental health system, there are general structures that are similar and may be familiar. There are many systems to navigate to receive the most helpful resource or support. These systems include but are not limited to: health care, community services, autism-specific organizations, community mental health services and social services. The table below highlights what some of these systems are.

Generally, there are few mental health supports for Autistic people and there is a lot of inconsistency, which leads to a lot of confusion for Autistic people and their family members. Services are often fragmented, which means they are provided separately from each other and may not know what other services are doing. Agencies may also try to give the same supports and approaches as are provided to non-Autistic people, without consideration for autism, and this may not be helpful.

|  | <p><b>What type of support is this and what is involved?</b></p>  | <p><b>What services do they provide?</b></p>  | <p><b>Who provides the support?</b></p>   |
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| <p><b>Autism-specific agencies</b></p>         | <ul style="list-style-type: none"> <li>• Gives specific support to Autistic people and to their families.</li> <li>• They may accept self-referrals or referrals from families.</li> <li>• After a first intake assessment, the person will be referred to the most appropriate service.</li> </ul> | <ul style="list-style-type: none"> <li>• Some agencies supply only one or two types of services (e.g., case management, therapy, education programs, social support, etc.).</li> <li>• These agencies may make a referral to a specialized service provider if they think it is needed.</li> <li>• The referrals may be fee-based, which can make the referral ineffective when affordability is an issue.</li> </ul> | <ul style="list-style-type: none"> <li>• Social workers, child youth workers (for under 18), psychotherapists, psychologists, therapy trainees, etc.</li> <li>• Some providers may not have the same training in autism, so the services may not be the same for each agency.</li> <li>• Some providers may not be trained specifically about mental health.</li> </ul>   |
| <p><b>Community mental health agencies</b></p> | <ul style="list-style-type: none"> <li>• Specific focus on mental health.</li> <li>• Their services may not be uniquely tailored to each person.</li> <li>• Services and supports may also be helpful to other family members.</li> </ul>   | <ul style="list-style-type: none"> <li>• These agencies may provide case management, counselling, group therapy, nursing and other kinds of mental health support.</li> <li>• They may also have recreational and vocational programs for people with mental health problems.</li> </ul>  | <ul style="list-style-type: none"> <li>• Social workers, child youth workers (for under 18), psychotherapists, psychologists, therapy trainees, etc. There may also be psychiatrists, physicians and nurses connected to community mental health agencies.</li> <li>• Providers may not have expertise in autism. They may be unaware of the approaches that are most effective when working with Autistic people.</li> </ul> |

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| <p><b>Primary care</b></p> | <ul style="list-style-type: none"> <li>• The day-to-day health care provided by a health care professional.</li> <li>• They can examine a person’s physical health and family history and rule out problems that could be adding to or changing a person’s mood, thinking or behaviour.</li> </ul> | <ul style="list-style-type: none"> <li>• At times, primary care providers can do a mental health assessment, particularly for more common conditions such as depression or anxiety. Sometimes, they will suggest that a person see a psychiatrist or other mental health professional.</li> <li>• A referral from a doctor is almost always needed before a person can see a psychiatrist. Family doctors often have a list of psychiatrists that they make referrals to, but the lists may not include psychiatrists with knowledge about autism.             <ul style="list-style-type: none"> <li>• Mental health referrals may vary depending on where you receive them. It can take between a few weeks, six months or a couple of years.</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>• Primary care providers (e.g., family doctors, nurse practitioners, family health teams) are often the first professionals that people talk to about a mental health problem.</li> <li>• Family doctors often do not have expertise of autism in adulthood. They may be unaware of the approaches that are most effective when working with Autistic patients.</li> <li>• Although family doctors or nurses may not have expertise in autism, they often have expertise and a long-term relationship with the patient, and sometimes the family.</li> </ul> <p>Given that understanding mental health problems in autism involves knowing how someone is different than their usual, the doctor can see how things are not the same. Also, they may have a trusting relationship and can connect what is happening in mental health with what is happening in other parts of health.</p> |
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| <p style="text-align: center;"><b>Hospital<br/>emergency<br/>departments</b></p> | <ul style="list-style-type: none"> <li>• An Autistic person can go to the emergency department of a hospital as a last resort.</li> <li>• If the situation does not require immediate medical care, the next step may be a more in-depth assessment from a crisis worker.</li> <li>• Sometimes these visits end up in hospital admissions, and other times care recommendations are made and the person returns home.</li> <li>• The clinical environment in an emergency department holds unique sensory issues for Autistic people, such as bright lighting, high-pitched sounds and random noises, all of which could be triggering and cause stress, adding to the experience of crisis.</li> </ul> | <ul style="list-style-type: none"> <li>• Services are provided for urgent medical attention, such as serious conditions and injuries.</li> <li>• There is access to a wide range of health care specialists and diagnostic equipment.</li> <li>• People do not need a referral to use this service.</li> </ul> | <ul style="list-style-type: none"> <li>• Often a nurse or social worker.</li> <li>• People may also see an emergency medical doctor or psychiatrist.</li> <li>• The emergency room can be an entry into inpatient psychiatric care if a person’s mental health is such that they cannot safely manage back home. Inpatient care settings in a hospital tend to work in partnership with hospital outpatient services with a goal of transferring care and making smooth transitions into the community.</li> <li>• Most hospitals do not have emergency room staff who are educated in the unique ways of communicating that can be a part of autism.</li> </ul> |
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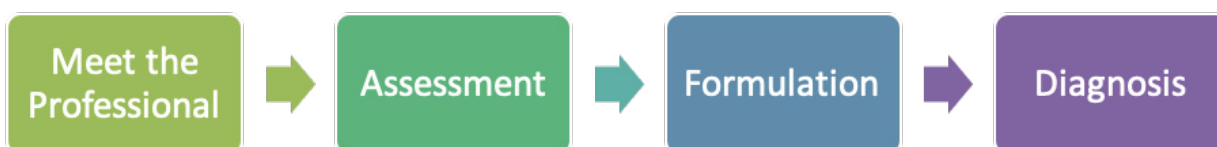
At all these settings, assessments may be completed to provide a starting point for support.

## Assessment

Assessments usually start with a conversation with the health or mental health care provider. Questionnaires are often part of the assessment. The health care provider investigates the reasons for why a person may experience mental health challenges, such as environmental and psychological causes.

### The process of identifying mental health challenges:

The following diagram shows a simplified process of identifying mental health challenges; however, the process may differ with every case.



The process begins with meeting a professional, and information is then collected through interviews or activities, including finding out the person's main concerns, their history and symptoms. Sometimes, more information is collected from a person's family or caregiver. From there, professionals review the information and communicate their first impressions.

A **formulation** is the term mental health professionals use to describe their impressions and conclusions that result from an assessment. Sometimes a formulation will include diagnostic labels (i.e., a diagnosis or multiple diagnoses), and other times the formulation will be more descriptive, such as describing the mental health challenge. The formulation is a summary of the entire assessment and is meant to pull all the information together to summarize impressions in a meaningful and helpful way.

## What are psychosocial supports?

The term “psychosocial support” can mean a few things. It can mean that it is a type of support that provides help through psychological and social methods. It involves psychological aspects of what the Autistic person is experiencing (e.g., how they feel, how they think and how they act) and the social aspect of support from others. The social aspects of “psychosocial” also acknowledge that an Autistic people’s feelings and behaviours may be influenced by, and related to, how they interact with other people.

The purpose of finding supports is to improve how a person feels and to help them to do things that they enjoy or love in life. It is important to know what types of supports are available to make certain that the right support is accessed.

## What are different types of psychosocial supports?

### Psychoeducation

Psychoeducation is education about mental health problems. People who know about their problems are better prepared to make informed choices. Psychoeducation is meant to provide information so that Autistic people may be better informed and prepared. Knowledge may help them and their families deal with their problems by increasing understanding of them, and may help people to make plans to prevent future problems. Psychoeducation sessions may include discussions about:

- what causes mental health problems
- the help that can be provided
- how to self-manage the problems (if possible)
- how to prevent future mental health problems
- what resources are available in a community.

### Psychotherapy

**Psychotherapy** is a type of psychosocial support that involves talking to another person, and for this reason it is sometimes called “talk therapy.” It helps people with their problems by looking at how they think, act and interact with others.

Psychotherapy can also be called “counselling.” Counselling is often used when the approach is focused on giving advice or decreasing immediate distress, rather than on helping with deeper change. Although lots of times, psychotherapy and counseling are used interchangeably.

There are many types of psychotherapies. Psychotherapy can be provided as one-on-one support or in a group situation. Sometimes the focus can be on the person, while other times it can be on a family or a couple. Most types of psychotherapy involve:

- one other person who is a professional
- sessions that are personal and private
- a focus on forming a healing type of relationship
- language to communicate (either spoken language, sign language, written language).

**Psychotherapy** can be either short-term or long-term:

- Short-term therapy has a specific focus and structure: this type of support usually lasts no longer than 10 to 20 sessions.
- In long-term therapy, the process is often less structured.

## What are different types of commonly provided psychotherapy?

### Cognitive-behavioural therapy

Cognitive-behavioural therapy (CBT) is based on the theory that thoughts (cognitions) have an important influence on how people behave and feel. There is research indicating that CBT may be helpful for some Autistic people to help with mental health challenges.<sup>1,2</sup> During CBT sessions, therapists help people notice thoughts (e.g., negative thoughts) and behaviours (e.g., harmful behaviours that result from those negative thoughts) that are unhelpful to the person, and help them to develop healthier ways of thinking and behaving (e.g., healthier skills and habits). In CBT sessions, the Autistic person and therapist may develop and select goals and strategies together. There is an emphasis on practising the skills between sessions.

### Trauma-informed therapy

Many psychotherapies focus on a person’s history of trauma. These approaches are often called trauma-informed therapies, which can include trauma-informed CBT as well. Some other types of psychotherapies that are meant to help a person cope with traumatic experiences include:



- Eye movement desensitization and reprocessing (EMDR): an integrated psychotherapy approach using guided eye movements to relieve negative feelings related to traumatic events.
- Emotion-focused therapy (EFT): a therapeutic approach that focuses on increasing emotion awareness, improving emotion regulation and the process of changing one emotion to another.

### **Dialectical behaviour therapy**

Dialectical behaviour therapy (DBT) is a type of cognitive-behavioural therapy. It is used to treat a range of behaviour and emotional problems. In DBT, people learn about how their personal background and life experiences affect how they control their emotions and how they interact with other people. It has been shown to be helpful for some Autistic people.<sup>3</sup> DBT combines Western cognitive-behavioural techniques and Eastern Zen philosophies. It teaches several skills that can help with emotion regulation and overall well-being.

These skills include:

- how to become more aware of thoughts and actions (also called “mindfulness”)
- how to tolerate distress and emotional pain
- how to manage emotions
- how to better communicate with others (for Autistic people, the] social-communication aspects can be talked about more openly, and these difficulties are validated)
- how to improve relationships with other people in an Autistic person’s life.

### **Acceptance and commitment therapy**

Acceptance and commitment therapy (ACT) encourages people to be okay with their thoughts and feelings rather than fighting or feeling guilty about them. ACT focuses on developing “psychological flexibility,” which is when a person is aware of, and connected to, their thoughts and feelings, and can stay with or change their behaviours in ways that lead to outcomes that are important (valued) by the person. ACT aims to validate a person’s difficulties and does not judge those difficulties. ACT combines mindfulness skills with self-acceptance. In the case of ACT, people may commit to facing problems head-on rather than avoiding their stresses, in a safe and supportive way. ACT may also aim to help a person understand their personal values by clarifying what is important to them in life.

## Family therapy

Family therapy is a form of talk therapy that includes at least one member of a person's family. The therapist helps the family members to communicate and interact in a healthier way together. A family therapist often does this by explaining the perspectives of the family members to each other, to improve the perspective taking of each family member about why the others may say or do certain things. The purpose is often to improve family relationships.

## Couples therapy

Couples therapy helps by reducing relationship distress. Romantic relationships can positively influence a person's life experience. However, maintaining a romantic relationship can be hard work that requires supporting and understanding each partner's needs. Couples therapy can be useful in any relationship (e.g., neurodiverse, Autistic or non-Autistic) where there are challenges that may include conflicts or difficulties with connection, intimacy or communication. For some Autistic people in romantic relationships, couples therapy may be useful to improve communication and understanding between romantic partners.<sup>4,5</sup>

## Psychodynamic therapy

Psychodynamic psychotherapy, also referred to as an insight-oriented therapy, is based on the theory that unconscious processes (which a person may not be aware of) influence choices and behaviour. This approach often aims to help people with unresolved issues that are often thought to have been caused by relationship problems in their past or from past traumatic events.

### Autistic experiences with psychotherapy

"I've done CBT and talk therapy—both I found helpful. Mostly I need someone to talk at who won't judge and may be able to 'see' the situation from a different angle and offer good, trustworthy advice. I also need someone to 'confess' to; if my thoughts are caught in a loop, if I have nasty intrusive thoughts that disgust me, if I think I've done something super bad, I need to tell someone or it will eat away at my insides until I'm in a panicked spiral."

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“I have had early language therapy when I was young, and in high school I’ve had CBT therapy for OCD, which did not help effectively. They tried using thought stopping, which does not work very effectively with people on the spectrum, at least not from my end and experience. What is most helpful, and validating, is talking to other Autistics that have had similar issues and understand your position and point of view. That’s on my angle. My cousin has had, and is having, therapy from a broken-up relationship and it really helps him on those issues. His brother, [who] is also Autistic but is higher support needs, has had speech and other therapy that was not as successful in the speech category and did not progress as much as what family wanted.”

## Other forms of psychosocial supports

Various other therapies may focus on a person’s sensory experience and may provide new ways to improve the ability to cope with distress and improve a person’s emotional state. They may also offer creative opportunities to express emotions and involve positive interactions with another person. These therapies are often meant to also build self-esteem or help a person to develop better ways of coping with stress.

### **Music therapy**

Music therapy involves a music therapist who works to build connections between a person’s emotions and the music that is either listened to or created in the music therapy session.

### **Art therapy**

Art therapy involves artistic expression helped by an art therapist. Just like music therapy, it connects feelings to artistic expression through the creation of art while focusing on feelings.

### **Peer support groups**

A peer support group involves a group of people who have similar difficulties. Group members can share their challenges in a safe, supportive environment. Sometimes peer support groups are led by a professional and sometimes they are led by a peer.

## Questions to ask when looking to take part in a group

1. Are they Autistic-informed or Autistic-led?
2. Does this group welcome new members?
3. Does the professional or group members respect me?
4. Is the group relevant to my situation, concerns and needs?
5. Are there any requirements for attending this group (e.g., a membership fee)?
6. Is the professional or group respectful and inclusive of members from diverse backgrounds (e.g., a range of cultural, gender, racial, religious and economic backgrounds)?
7. Do the sessions or group offer both support and education?
8. Are the individual or group sessions ongoing or is it time-limited?
9. Does the professional or group have a positive attitude toward professional help for families?
10. Who helps the session or group, and how is the group process managed?

### **Animal or pet therapy**

Animal-assisted therapy incorporates the use of animals, such as dogs or horses, to help people cope with mental health difficulties (e.g., anxiety, depression). Animals may provide comfort or alert if a person is in danger. The type of animal therapy can vary depending on what the person's challenges are.

“If one treatment doesn't work for you, you *haven't* failed, it's just not a good fit. Try another, and another one. In the end, you may find something that works for you. But if not, *don't* think you are too broken, when it's the failure of the system to properly support you, not your failure.”

## Finding a good support person or therapist

Successful therapy can depend on having a supportive, comfortable relationship with a trusted support person or therapist. Many different kinds of professionals can be therapists, including doctors, social workers, psychologists or others. Therapists can be trained in different types of psychotherapy. They may work in hospitals, clinics or private practice.

Below are some things to consider before choosing a therapist:

- The personal aspect of feeling connected with that person. As one adviser said: “It's okay if you don't like them, you can find another therapist.”
- Trust your gut when deciding if you like your therapist or not. If you feel bad whenever you are around them and you don't know why, it may not be the right place for you.

For some Autistic adults, it may be important that the therapist has experience with autism. It is okay to ask the person if they do. Finding a therapist with expertise or specialization in autism may help to avoid experiences that are not helpful.

Advisers outlined the following things to look for and things to watch out for when seeking a good support person or therapist:

| Things to look for  | Things to watch out for   |
|---|---|
| <ul style="list-style-type: none"> <li>• They ask for consent.</li> <li>• Really listens to what you say, even when they disagree.</li> <li>• Willing to listen and work with your needs/wants.</li> <li>• Open-mindedness and willingness to learn you.</li> <li>• Focuses on understanding why you act/feel the way you do.</li> <li>• Gets your input about why you act/feel the way you do.</li> <li>• Accepts your Autistic traits (such as stimming, echolalia, lack of eye contact, sensory needs): <ul style="list-style-type: none"> <li>• Doesn't try to reduce or get rid of your Autistic traits.</li> <li>• Doesn't interpret Autistic traits as symptoms of some underlying condition.</li> <li>• Gives all relevant information so you can make informed decisions rather than making decisions for you.</li> </ul> </li> <li>• Understands the difference between a meltdown and a tantrum (if applicable).</li> <li>• Looks for different ways to communicate, that work for you (if applicable).</li> <li>• Respects your rights a person and your identity.</li> <li>• Is honest.</li> <li>• Is patient.</li> <li>• Focuses on emotional well-being.</li> <li>• Sets good boundaries.</li> </ul> | <ul style="list-style-type: none"> <li>• Is dismissive of things you say when they disagree.</li> <li>• Is not interested in why you act/feel the way you do.</li> <li>• Ignores your input about why you act/feel the way you do.</li> <li>• Pathologizes Autistic traits (such as stimming, echolalia, lack of eye contact, sensory needs).</li> <li>• Tries to reduce or get rid of Autistic traits.</li> <li>• Interprets Autistic traits as symptoms of some underlying condition.</li> <li>• Withholds information to get you to make decisions that they think are in your in best interest.</li> <li>• Doesn't understand the difference between a meltdown and a tantrum (if applicable).</li> <li>• Insists that speech is the only acceptable way to communicate (if applicable).</li> <li>• Focuses on weaknesses.</li> <li>• Expects you to be able to advocate for your needs when you are not able to.</li> <li>• Puts you down.</li> <li>• Doubts your autism diagnosis.</li> <li>• Is unwilling to accommodate or be flexible to autism-related challenges.</li> </ul> |

## Autistic experiences with psychosocial supports

“I have had mostly bad experiences with psychosocial supports, largely due to the fact that about half of these were provided at a gender clinic, which I found very unpleasant for many reasons. I urgently wanted hormone therapy, but it took me years before he gave me a referral. Any benefits the talk therapy could have given were outweighed by the lack of autonomy I experienced and the stress of not knowing when or if I would get the treatment I actually sought.

“This bad experience coloured future interactions with psychosocial professionals—I would say trauma caused by bad experiences is one of the most prevalent problems clients of these services face.”

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“I have not used or needed to try psychosocial supports since I graduated high school. However, my middle sister currently does an online dance therapy class twice a week that is conducted by a therapist we had when we were younger. Tips that I can provide [are]: Be honest with yourself when deciding whether the psychosocial support you are currently using is working for you or not. If it’s not, move onto something else; but if it is, stick with it. Also, ask the social networks that you do have to help you find psychosocial supports that you can access and can try (e.g., try to find ones that are in your local community). Doing your own research on the subject would also help, too.”

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“My baseline question nowadays for anyone that I am seeking help from is if they have an actual working familiarity with autism and Autistic people. I have been given bad therapists, bad medications and bad supports that have harmed me and made me feel as though—even when I am actively seeking help—I am still failing or doing something wrong. I have been labelled ‘non-compliant’ for not being able to do what has been recommended for me to do, even though they are causing me harm. These days, I tend to grill care providers ahead of time to ensure that I will receive quality care, but this also yields suboptimal results because it tends to put people on the defensive, even though I am just trying to make sure that they are even able to help me before I make myself vulnerable to them.”

## Considering medication as mental health support

Medication can be an important part of mental health support. In many cases, medication may be helpful if it is combined with some psychosocial support or community care (see **Section 6**).

**Caution:** Always consult with a qualified medical professional if you would like to know more about medications, including those mentioned here.

### Medications for mental health problems

When a person experiences a mental health problem (e.g., a mood disorder, an anxiety disorder, schizophrenia), medication may be one part of an overall support plan. Medications that affect how the brain works and lead to changes in emotions, thoughts, feelings or behaviour are known as “psychotropic medications.” These kinds of medications mainly aim to adjust chemicals in the brain to reduce symptoms. This can help to reduce the frequency or severity of difficulties. There are some common types of medications, which are divided up based on the problems that they were originally developed to treat:

#### Antidepressants

Antidepressants were originally used to treat depression, but they are used for lots of other reasons, such as chronic pain, bulimia, premenstrual dysphoric disorder, chronic fatigue syndrome and anxiety disorders. In fact, antidepressants, especially the kind known as selective serotonin reuptake inhibitors (SSRIs), such as Prozac, are used more often to treat anxiety problems than are traditional anti-anxiety medications, like Valium.

#### Mood stabilizers

Mood stabilizers are used to help control mood swings (extreme highs and lows) often connected to bipolar disorder, and to prevent further episodes of this condition. Lithium was the first mood stabilizer and is still considered a useful medication. Other medications used to stabilize mood include anticonvulsants, which were originally developed to treat epilepsy as diazepam (Valium) and lorazepam (Ativan). While they are legitimate medications for treating anxiety and sleep disorders, they can become



extremely addictive if used daily for more than four weeks. An anti-anxiety medication that can be used for a longer period of time is buspirone (BuSpar).

### Anti-anxiety medications/sedatives

The main group of medications of this kind consist of benzodiazepines, such as diazepam (Valium) and lorazepam (Ativan). While they are legitimate medications for treating anxiety and sleep disorders, they can become extremely addictive if used daily for more than four weeks. An anti-anxiety medication that can be used for a longer period of time is buspirone (BuSpar).

### Antipsychotics

Antipsychotic medications often aim to reduce the effect of dopamine (a chemical) in the brain. They are traditionally used to treat schizophrenia and other psychotic disorders. The newer antipsychotics are now also being used as mood stabilizers, as anti-anxiety medication and as a medication for depression.

### Stimulants

Stimulant medication increases the activity of different neurotransmitters in the brain, such as dopamine and norepinephrine. They are often prescribed to increase a person's ability to focus and concentrate and reduce hyperactivity, which is when a person can find themselves being overly active and impulsive. Common stimulant medication includes Adderall, Concerta and Ritalin.

## Medications for symptom management

Using medication for mental health problems for Autistic people can be complex. Most of the research that has been done on medications for mental health problems has been done with non-Autistic people.

Improvements vary from person to person. Finding the best medication for each person should be done carefully and in consultation with a medical professional or team. It is important to know what each medication is targeting and what the problem looked like before starting a medication, to see how the problem improves with medication. **Autistic people should be involved in the decision-making process and be given information about the benefits and risks, including the side-effects of medications.** It is important to be aware that medications can interact with one another; ask the doctor about this to prevent problems.

There are a number of useful questions to ask a prescribing doctor about medications:

### Questions to ask a doctor about psychotropic medication

1. What is the name of the medication, how does it work and what is it supposed to do?
2. How and when is it taken, and when should a person stop taking it?
3. What food, drinks or other medications should be avoided while taking the prescribed medication?
4. Should the medication be taken with food or on an empty stomach?
5. Is it safe to drink alcohol or use recreational drugs (e.g., cannabis) while on this medication?
6. What are the side-effects, and what should be done if they occur?
7. Have all areas been considered, such as nutrition, sleep, hormones, other medication?
8. Where is information about this medication available?

### Identifying and minimizing side-effects

**It is important to understand that almost all medications have the potential for side-effects.** Not everyone experiences side-effects, or to the same degree, and there are often practical solutions to dealing with them. Sometimes side-effects can be a problem when an Autistic person is taking different medications at the same time. Sometimes side-effects can happen when the medication dose is too high for them, and lower doses may be just as helpful and have fewer side-effects.

It is important to pay attention to side-effects because they can lead to more distress or more problems, and an Autistic person needs to be able to share their experiences with the medical team. Careful monitoring is essential, especially when the person taking the medication cannot communicate their experience with the medication and report side-effects. Along with having a support team (i.e., a group of people who can supply support: family, doctor, pharmacist,

therapist, friend, etc.), it can be helpful to note potential side-effects of each medication and figure out ways to watch for them.

Side-effects may increase or decrease over time and can range from mild discomfort to problems that are severe enough to make it impossible to cope with day-to-day life. People often stop taking medication because of unpleasant side-effects without reporting them to anyone. **It can be dangerous to stop or change medication without consulting a health care professional.**

A support team can suggest ways to minimize side-effects. Strategies include:

- taking the medication in smaller doses spread over the day
- taking medication with food
- taking another medication to treat specific side-effects
- changing the time of day that the medication is taken
- changing the medication.

It is sometimes surprising how much of a difference even a very small adjustment can make in how someone responds to medication or in how a person is affected by side-effects. For example, while a higher dose may be needed at certain times (e.g., if symptoms of anxiety are worse because of a prolonged stressor), a person may at different times be able to have the same relief from their symptoms at a lower dose. How much medication a person takes may also need to be changed over time.

Some Autistic people may not feel listened to by their doctors or may feel that their doctors are not being upfront about medication side-effects or that they are downplaying them. Some Autistic people may be concerned that a doctor will be upset if a patient decides not to try a medication that was recommended or decides not to continue on a medication. An Autistic person may benefit from taking someone (e.g., a relative, friend or mentor) with them to doctor appointments, to ask questions about medications and their side-effects.

### **Autistic experiences with medication**

“Antidepressants helped me ‘tread water’ emotionally when I was at my lowest points, but I certainly do not see them as adequate permanent solutions for me. A band-aid doesn't heal the root cause of a wound.”

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“I have been on Abilify, which I found did not help at all. I have been on venlafaxine, which might have helped initially, but eventually I felt like I was as depressed as before. Alarmed by the possibility that I might be developing a tolerance, and that this might make my depression worse in the long term, I talked to my psychiatrist about gradually going off it. He did not support this, and meetings with him were few and far between. So, I took things into my own hands and went off ‘cold turkey,’ against the advice of everybody who cared to give it. I was very sick for about a month, but I was not busy at this time, so I could suffer through it without real loss. At the end of it, I actually felt much better. I am not sure whether this was a chemical effect per se or due to the pride of having gone off a drug notoriously difficult to get off. I wished I had known when I first agreed to take it just how difficult it is to get off a drug like that.”

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“I have been on Zoloft for over 10 years. Generally, it has really helped. I take it every day. When I was younger, a psychiatrist I had seen said he wanted to put me on a low dose of an antipsychotic medication along with the 200 mg of Zoloft. It was very effective for a while, but neurological side-effect symptoms which I was warned could be permanent started, even if being small at first. The risk of being on a certain drug of high power such as an antipsychotic medication was a risk I should have been told about from the get-go, but that was a long time ago. A list of side-effects is always helpful to watch for. No matter how small.”

## Medication interactions

Medications are used to treat different problems and they may work differently when combined with each other, so it's important that the person who prescribes the medication has a complete list of medications that a person is taking. A medication interaction is when one medication changes the action or effects of another medication. Some interactions may have minor effects, while other ones can be dangerous and even life-threatening.

When medications are taken together, they may:

- Act independently of one another.
  - For example, alcohol does not seem to interfere with the action of vitamins or oral contraceptives, or vice versa.
- Increase each other's effects.
  - This could happen because each medication affects the same brain system or because one drug changes the concentration of the other in the body. For example, alcohol and antihistamines are both central nervous system “depressants.” If taken together they can increase the effect of the depressant, which can be dangerous.
- Decrease each other's intended effects.
  - This could happen when one medication “blocks” or prevents the effect of the other medication. It could also happen when two drugs have opposite effects on the brain.

## Monitoring medication

It is important to make sure that an Autistic person and/or their family member or trusted person knows the name and dose of each medication they are taking and why it has been prescribed. The easiest way to do this is to get a printout from a local pharmacy that lists current and past prescriptions. This information should be stored in an accessible place in case there is an emergency or a visit to a doctor who does not have a current medication list on file. Here are some things to consider when monitoring medications (see Activity 7.1):

- Rank symptoms of the problem on a scale of 1 to 10 (where 1 is “no improvement” and 10 is “a lot of improvement”) and report any improvement.
- Track emotions and behaviours in a journal to figure out if a medication is working (e.g., what happened when a certain dosage was changed?).
- Note side-effects and discuss them with a support team.
- Check with a doctor and/or pharmacist for medication interactions before taking any new medication (prescription or over the counter).
- Input is important when making medication changes. Report on how the change is going: Are symptoms worse? Are side-effects better?
- It is also important to review medications every so often, and it is okay to ask your health professional to review them with you.

## Activity 7.1 – Medication and Side-Effect Tracking

This sheet can be used to monitor medication and side-effects.

| Date | Medication | Dose | Symptom | Symptom improvement<br>(rate from 1-10) | Side-effects |
|------|------------|------|---------|---|--------------|
|      |            |      |         |   |              |
|      |            |      |         |   |              |
|      |            |      |         |   |              |
|      |            |      |         |   |              |
|      |            |      |         |   |              |

At times, it may be impossible to know how much of a change is due to a change in a person's life situation and how much is due to a medication. If there are significant life events or changes in an Autistic person's routine or living situation, consider pausing any changes to medication.

### Ongoing medication

In some situations, medication will be short-term, as in the case of a sleeping pill for temporary difficulty with sleeping. For an episode of depression, medication could be longer term. For schizophrenia, the period of medication could be indefinite to prevent symptoms from returning. Some mental health problems are lifelong, so support with medications may be ongoing. Others are temporary, so it is important to examine whether the medication should be continued by having regular medication follow-up appointments.

## When medications are not working

It is important to give feedback to a support team or health professional about how well medication is working. Any time a new medication is prescribed, it is a good idea to schedule a follow-up meeting to consider whether the medication change is working.

Some Autistic people with mental health challenges may be prescribed medications without proper monitoring and follow-up. Some medications require regular monitoring for side-effects (e.g., regular blood work to monitor the effects of antipsychotics on the body). Once medications are prescribed, a regular review of current medications, their effects, side-effects and the need for each should be undertaken (e.g., as part of an annual medical check-up or more regularly if mental health symptoms are not adequately treated).

## Stopping medication

Autistic people and their families can feel uncertain about long-term medication use. They may want to stop their medication because they:

- experience unpleasant side-effects
- feel well and no longer see the need to take medications
- get messages from others that medications are harmful and not necessary
- have concerns about medication interactions.

Stopping medication should be supervised by a qualified health professional. Stopping or changing medication should be done carefully; usually a gradual approach is important rather than a sudden stop.

Medication can be an important part of support for Autistic people with mental health challenges, but finding the most effective medication, or combination of medications, can be a long, frustrating process. It can be helpful to learn about the benefits and risks of the medication and to talk to support persons or your doctor about how the medication is working and its side-effects. Making sure that the medication and dosage are reviewed regularly is also helpful. It is also okay to ask for a second opinion.

## References

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