



RECEIVING AN AUTISM DIAGNOSIS LATER IN LIFE

a self-advocate perspective

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Introduction

Being diagnosed as autistic when you are an adult can be an intense experience. Finding out that there is a reason for your experiences and/or lifelong struggles is often overwhelming. However, finally understanding why you may have felt out of place in the past can also be empowering. This toolkit was created to support those experiencing this exciting, but sometimes emotional, transition to self-acceptance. It provides some helpful information and lived experience with the hope that it will be useful to those beginning this journey.

This primary author of this toolkit, Rebekah Kintzinger, was diagnosed as an adult. She created this toolkit to share her experiences and the lessons she has learned since receiving her diagnosis.

While this toolkit was written for you, a newly discovered autistic adult, you can also pass it on to your family, friends, and significant others to help them understand what you are going through.

Welcome to the next chapter of your life: may your journey be filled with self-understanding and hope.

A note on defining and describing autism in this toolkit: **Autism is a neurological developmental difference that can affect social and communication skills.** There is no “cure” for autism, and curing autism should not be a goal. Autistic people contribute a valuable and unique perspective and can play an important role in society. **Being autistic does not mean that there is something wrong with you.** In fact, you may notice that there are several things that you can do exceptionally well!

PART 1: GETTING A DIAGNOSIS AS AN ADULT



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With everything we know about the autism spectrum today, you might ask yourself how is it possible to receive an autism diagnosis later in life? Or maybe you wonder why no one diagnosed you when you were a child? If you would like to know more about what research studies have found about the potential obstacles to getting a timely diagnosis, please [click here](#) to access our document “Research Summary: why more people weren’t diagnosed as children”.

The process of getting a formal diagnosis can be extremely time-consuming and expensive. Some waitlists are years long – if they even allow you on a waitlist at all! Some people get frustrated and feel like they can’t move forward until they receive that piece of paper saying they are autistic. While you may have to wait to access certain programs or accommodations, there are things you can do now to start to improve your life!

Formal diagnosis vs. self-diagnosis

Many people who have either a formal or self-diagnosis of autism have described a sense of relief and self-acceptance after recognizing that they are on the autism spectrum. Knowing which form of diagnosis is best for you depends on your needs.

Formal diagnosis

A formal diagnosis of autism is made by a trained specialist. Usually, the first step is to be referred to a specialist by your physician. A formal diagnosis involves several tests, interviews, and evaluations to determine whether an autism diagnosis is appropriate. In Canada, only physicians, including psychiatrists, and psychologists are qualified to diagnose autism.

Getting a formal autism diagnosis is not an easy process at any age, but this is especially true for adults. The waitlists for professionals can be many months or even years long, and some will only diagnose younger people. The fee to get a formal diagnosis can be costly and might not be covered by your extended health benefits.

Self-diagnosis

A self-diagnosis is when you identify that your experiences are consistent with someone who has an autism diagnosis before you get an official diagnosis from a specialist.

Due to the previously mentioned barriers to formal diagnosis, many adults begin by self-diagnosing. If your support needs are low, self-diagnosis can give you a sense of relief and may help you connect with others who have similar experiences. Communities of autistic adults often support one another and help find tools needed to better manage daily life.

Making the decision on which type of diagnosis to pursue:

If you are looking for formal accommodations or supports, self-diagnosis will not be enough to connect you with such resources. Resources like the *Persons with Disabilities Program* or the *Disability Tax Credit* require a formal diagnosis and a physician must fill out portions of the application. School and/or work accommodation forms usually require proof of a formal diagnosis of autism.

If you think you might need support or accommodations, you might want to pursue a formal diagnosis. In addition to getting access to their desired supports, many autistic adults have described that formal diagnosis brought a sense of relief and legitimacy to their life experiences.

How do I get a formal diagnosis?

Getting a formal diagnosis can require different steps depending on where you live and what sort of resources are available. **You may have to travel to find someone who diagnoses adults.** The first thing to do is to decide if you are able to pay for a private assessment. The cost is usually between \$2000 and \$4000, but the waitlists are usually shorter.

It is also possible to get a diagnosis from a specialist whom may receive funding by the Provincial/Territorial Health Authorities. These assessments may be covered by public funders and may be free to patients. Unfortunately, there are not many of these specialists available in Canada, and the waitlist can take years before you get an appointment. Some will not even accept new people on their waitlists at all because they are already too long!

If you are looking for a formal diagnosis, please click [here](#) to read our article: "Steps to getting a formal autism diagnosis as an adult in Canada."

If you are wondering what to do while you wait for a formal diagnosis or are still deciding if your self-diagnosis is accurate, please click [here](#) to read our article: “Being diagnosed with autism as an adult: What should I do while I wait for a formal diagnosis?”

PART 2: I HAVE BEEN DIAGNOSED, NOW WHAT?



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Some people have described the moment they learned about their autism diagnosis as a ‘line in the sand’, ‘fork in the road’, or an ‘aha moment’; where things from their past started to make sense^[22].

Many Autistic individuals have reported that they felt lost or like they ‘did not belong’ prior to getting a diagnosis and feel more confident after they have a diagnosis^[23]. **When you know why you feel, respond to, and experience things differently, you can better manage challenges.** You can learn to accept yourself and move forward with greater confidence. You can also use your knowledge to educate others, and bring awareness and acceptance for yourself and others on the autism spectrum.

You may also experience self-doubt and wonder if an autism diagnosis is really the correct one for you. In this final part of the toolkit, we focus on reflecting on your diagnosis, finding a new normal, accepting your diagnosis, considerations around disclosing your diagnosis to others, and advocating for yourself.

Reflecting on your diagnosis

A diagnosis can help you make sense of the past and help you to view previous events and experiences in a new light.

In other words, **getting diagnosed can be a turning point where you realize that you do not function like many others, and there is nothing wrong with that!** Events in childhood, for example, may have left a negative impact because of the way you were treated. Looking back with an autistic lens may help you come to terms with some of the

negative experiences of the past. For instance, you may have felt like you did not “fit in” and have experiences of being excluded or bullied. It can be empowering to know why you do things differently and that it does not make you “weird”. It just means that you do things in a more autistic way. **Social struggles or challenges in school, university, or at work now have an explanation, and can be approached with new solutions.** Sensory processing issues and food avoidances are not because you were being “being fussy for no reason”, rather, there is a neurological reason for them.

You may choose to learn a lot more about autism after you are diagnosed. This can help you better understand your autistic traits and behaviours ^[22].

The more self-aware you are, the more control you have over your life.

A diagnosis of autism can validate your experiences and help you make informed decisions based on your personal strengths and challenges.

Finding your new normal

Adjusting to your new normal may be easier as you learn about autism and how it affects your life and behaviour. After learning that you are an Autistic person, not a difficult person for example, you might be able to let go of some negative stereotypes or descriptors that you may have heard from others as you were growing up.

As you move forward, you may now ask yourself “are there things in my life I want to change”? Getting to know what you need, and what you need to avoid to be at your best, can improve your quality of life. Those adjustments do not have to be major changes; they can be quite small, but go a long way. One example of an easy way to better meet your needs is to create and carry an ‘On-the-Go Kit’.

Creating an On-the-Go Kit

Carry a bag with the tools you need to support your sensory needs and/or anxiety in public

Common items:

Earplugs/Headphones Scarf/toque Favourite fragrance Snacks/Water ‘Stim’ items

Navigating doubt after your diagnosis

Feelings of self-doubt

You may experience self-doubt after your diagnosis. You may have learned to adapt to neurotypical life by hiding your autistic traits to the point where you feel like the diagnosis is not accurate. Coping strategies are often used by Autistic people to reduce the anxiety felt in everyday situations. The strategies and coping mechanisms that you may have developed during your life to help you blend into a neurotypical world, do not mean that you are not Autistic. If you received a formal diagnosis, you can remind yourself that the professional who diagnosed you is highly trained and would not “give out” a diagnosis if they were not certain of it.

Ableism and internalized ableism

One major challenge you may encounter as a person receiving a late diagnosis is related to ableism and internalized ableism.

Ableism the discrimination and oppression that is experienced by individuals with disabilities in favour of people without disabilities^[25].

Internalized ableism comes from the idea that your value as a person is based on your productivity and how well you fit in with society

Internalized ableism does not happen on purpose, but it is the result of hearing, year after year, messages such as “you’re just not trying hard enough”, “you could do ____ if you were just willing to make the effort” or that “with a potential like yours, how come that you have not achieved ____”. If internalized, it often translates into someone experiencing low selfesteem because they cannot perform as others make them think they should. Other examples of internalized ableism include expecting yourself to be able to easily manage socializing in an environment that is not suited to your sensory needs or not needing any accommodation to maintain a job. In the longer term, it can lead to *autistic burnout* if you keep exhausting yourself by trying to be someone you are not (for more information on autistic burnout, please see our toolkit [here](#)).

Additionally, people who have been labeled as “high functioning” may experience unrealistic expectations of themselves or by others. People may not understand why you can do a certain task easily, but struggle with another apparently similar task. **They may be more likely to assume that you do not need support and might be critical if you try to advocate for yourself.** On the other hand, someone could suggest that if an Autistic individual is non- or minimally-verbal, they are presumed to be “low functioning” when in fact they have many abilities. Creating such labels is judgmental and has a divisive effect within the community.

Masking

Masking and camouflaging is suppressing, or hiding autistic traits and behaviours.

Autistic individuals do this to blend in and be perceived as more neurotypical in environments where they could potentially experience rejection and discrimination^[12].

Masking is not always a conscious mechanism and it can be linked to trauma^[26].

Masking and camouflaging and constantly 'performing' can be draining and can hurt you in the long run. If you are socially accepted only when you are 'masking', you are not being accepted for who you really are. This is yet another way that your self-esteem could be impacted. Now that you know you are autistic, you may try to mask less.

It could be time to explore aspects of yourself or your needs that you have been hiding in public or not addressing as well as you could. A diagnosis can give you the freedom to "experience" your autistic traits without having to hide them. This may be liberating, and could lead you to be a lot less hard on yourself. It is time to be kind to yourself and be aware of your own personal needs. Importantly, this could translate into a better mental health.

Self-compassion

Be more flexible and understanding with yourself. Realize that the things you have had trouble with are not because there is something wrong with you. Instead, focus on the fact that you are your own person and you think and operate in your own way. This realization can help you to allow more space and time to grow and adapt to the challenges in your life. Instead of getting frustrated or critical of yourself for not doing something "the way it's supposed to be", you can learn new ways to manage challenging situations. Knowing that you can do things differently can help reduce stress in your life.

There are lots of things that autistic people cannot change about themselves. **Getting a diagnosis can help to identify specific areas that could be worked on if needed, but also to let go of impossible struggles and highlight areas of strength.** For example, you may have a low tolerance to frustration. Instead of just expecting yourself to 'deal with it', you now might accept this trait and try to work around it by finding ways to prevent the frustration in the first place. This allows you to honour who you are, and work to build skills to better navigate frustrating situations. It wasn't until I learned I was Autistic and gained knowledge about the autistic spectrum, I was able to link some of my traits with Autistic traits and begin to work on them to improve my selfawareness. For example I didn't realize that I struggled with perspective-taking before my diagnosis, now I am better able to take the perspective of others and I've worked on skills specifically related to communicating with people, turning some challenging areas into less challenging areas.

Self-care

Self-care should part of your routine, and is one of the first steps you can take towards maintaining your mental health. As suggested earlier, scheduling time to do things you personally enjoy should be a regular part of your routine. It can take many forms, depending on what you need and like. If you are not sure about what you enjoy doing, you may want to explore options to discover what could be beneficial and soothing for you. Below are a few ideas to consider:

- Down time can be overlooked as there is a pressure to always be productive or just “do”. Acknowledging that you need quiet moments to recharge, and respecting that need, can be nurturing.
- Identifying your needs and setting boundaries for yourself and others can help you regulate and avoid exhaustion. Saying no is self-care!
- If you have difficulty relaxing and are okay with deep pressure and being touched, massage therapists can help you explore relaxation therapy. If you do not like to be touched, self-massage or weighted objects (lap pad, cushion, neck pillow, etc.) may also help you to relax.
- Exercise can help with emotional regulation and physical health. You could try to find a physical activity you like or ask a personal trainer to help you navigate options. If you already know that you like sports, you could make it a regular activity, with a friend or even a group.
- If you know that you have a hard time being physically active at certain times of the day or night, schedule physical activity according to times that work best for your personal rhythm.
- Eating well is important for your overall health, even if you have some dietary restrictions. Explore new types of food options and/or learn novel ways to prepare what you like.
- Some autistic people have difficulty determining when they are tired, hungry or thirsty.
Regular check ins or the use of alarms can remind you to take breaks, have a snack, etc. Eating well and consuming sufficient fluids may avoid dehydration or headaches.
- If you live independently, try to set up a daily and weekly routine that allows time for everything that needs to happen (e.g., cleaning, cooking, laundry) as well as free time for yourself to recharge.
- If you easily feel overwhelmed by complex tasks, try breaking them into smaller chunks to create a step-by-step guide.
- Rely on planners, apps, and a calendar to relieve the pressure of daily life.

In addition to these helpful tips, **you can capitalize on your preferred interest** if you have one ^[28]. Even if no one around you appreciates what you’re doing, embrace it and make time to do what you really like! Just be mindful that you will still have to maintain a certain balance with mandatory tasks and chores. If you think you will have some difficulty to manage the time you spend on your activities, you could schedule ahead of time and set a timer, if needed.

Stimming

Allow yourself time to stim more: Stimming or stims refers to self-stimulating or self-soothing behaviors. Stimming does not always translate into the infamous hand flapping; it can be more subtle, such as gently rocking back and forth. **For a lot of autistic people, stimming is an outlet for stress and can reduce anxiety and help you feel calmer.** You may have been taught as a child to hide your stimming in front of others so you wouldn't be teased. In the beginning, you may only feel comfortable stimming when you are alone or if you are with people you trust.

Non-verbal communication

You may learn to think differently about communicating with others. **Processing verbal communication can be exhausting!** Some people find it helpful to give themselves extra time to process verbal information or limit their interactions to take place in less overwhelming environments. Oral communication is a powerful tool, but it can be draining to have to consciously interpret what another person is saying and decide on an appropriate response. In addition to the verbal content, one also must consider tone, vocal inflexions, facial expression, body language, and filter out confusing sensory input. **Being aware of the extra-steps needed by the Autistic person to communicate in a neurotypical environment can allow you to reframe and plan interactions with others. It may also help others to gain understanding and provide needed communication support.**

Boundaries

Establishing boundaries can prevent autistic burnout ^[27], which is a period of distress and exhaustion in areas of life. **Clear communication is key to establishing good boundaries.** Sometimes a communication support or therapy can be helpful to determine needed boundaries and how to assert them in a healthy way. **Saying 'no' is not always a bad thing, and people who care about you should not resent you for that.**

In considering what would be helpful to you or what you might want to change, weigh the pros and cons of each potential change and ask yourself **"is the cost of changing this behaviour or trait greater than the benefit that will come from that change?"**. It is not an easy or quick process and it can be overwhelming at times to change aspects of yourself or your life. Take your time and discuss it with people you know and trust.

Preparing to seek help

Seeking help can be stressful. For example, when you meet with a health care professional, it may feel overwhelming. Here are a few ways to prepare yourself ahead of time:

- **Try doing some research** if you feel you want to know more about that specific topic prior to the appointment.
- **Have notes and lists of questions** written down prior to the appointment.
- **Write things down** if you have a hard time processing information verbally so you can go over your notes later and you have a physical copy of what was said.
- **Ask the professional to clarify if you need help understanding or if you are having difficulty processing the information.** There is no problem with asking your health professional to accommodate your needs.
- **When it is possible, bring someone you trust with you:** if you experience anxiety during an appointment, it can be very helpful to have someone with you. Your friend or advocate will be able to support you during the appointment.

Mental health and therapy

Self-care is a constructive ‘first step’ to caring for your well-being. But sometimes, it will not be enough – specifically if you are going through difficult times or processing something significant and negative that has recently happened. Mental health support and therapy exist for all sorts of problems and can be helpful to Autistic individuals. For example, if you struggle with anxiety, it can be addressed through therapy. **It is up to you to decide whether you need support.**

Autism may not be the only diagnosis you received after going through a full assessment. Cooccurring conditions are extremely common in autism ^[6, 7, 24], so you may discover that you have also been living with an anxiety disorder or a learning disability such as dyslexia or ADHD. Note that this toolkit only addresses autism, but learning more about co-occurring conditions can help you find better supports and accommodations for your unique needs. [The AIDE Canada lending library has free books and e-books that can give you more information about other common diagnoses.](#)

Should I go to therapy? Autism has ‘ups and downs’. Psychological therapy can substantially benefit. The point of therapy is to help you gain the skills you need to live your best life, and can help you feel more prepared to navigate the world.

A lot of autistic people have had experiences that need healing or to be processed once they have a diagnosis of autism. **When someone is first diagnosed as autistic, they may experience intense emotions.** Looking at the past through the perspective of autism can bring healing. Some of that healing may happen on its own just by taking some time to deal with issues. But for difficult and/or longstanding issues, the help of professionals may provide a level of support that nurtures more rapid resolution and health. As an example, trauma may be linked to certain experiences. Some Autistic individuals are also diagnosed with Post Traumatic Stress Disorder (PTSD) following aversive life experiences ^[29, 30]. Professional support can be particularly helpful while reprocessing traumatic memories.

If you are considering a therapist, choosing the right therapist for you is important. Note that many forms of counselling and therapeutic approaches are not geared to autism.

Knowing you are autistic can guide decision-making in seeking services suited to your needs. Below are a few evidence-based options:

- **Occupational therapy** can help with sensory overwhelm, 'shutdowns', and hyperstimulation. You can develop strategies that will help you calm yourself when the world feels overwhelming. An occupational therapist (OT) trained in sensory processing can assist with proprioception, which is the sensory system that allows awareness of your physical body in relation to space and objects. An OT can also help with developing a better awareness of interoception, which is the sensory system that helps you recognize what is happening inside your body. With better recognition of how you are responding to what is happening around you, and how you are feeling inside, you can better recognize when you becoming overwhelmed and make adjustments before you have a negative reaction.
- **Speech therapy** can help you communicate more effectively, get better at understanding verbal communication (i.e.: idiomatic expressions), and gain confidence in your ability to speak to others. Speech Language Pathologists (SLP) trained in autism may also help with recognizing other aspects of communication, for instance, interpreting tone and body language.
- **Counselling** can be a helpful way to process life issues. It can help you gain confidence in yourself. A therapist can help you work through possible traumas of being autistic yet growing up without a diagnosis. It can also be an outlet to express what you may struggle with in a judgement-free environment.
- **Support groups** may help you readjust after being diagnosed with autism. Groups offer a safe space to share and reflect on your experiences. They can also be a resource to help normalize one's feelings and life experiences. Some autism support groups are even geared toward specific sub-groups such as women or LGBTQ2+ individuals. Ask around in your community to find out which groups are meeting in your area or online.
- **Cognitive Behaviour Therapy** (CBT) helps people to identify and question thoughts, attitudes, and beliefs that are contributing to difficult emotions and behaviours. CBT allows people to 'reframe' their thoughts to be more productive and helpful and develop practical skills to better manage their lives.
<https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/cognitivebehavioural-therapy>
- **Dialectical Behavioral Therapy** (or DBT) has some overlaps with cognitive behavioral therapy in that it also helps to identify and change negative thought patterns. However, in DBT the focus is more on regulating intense emotions and/or self-destructive behaviours. It can help an individual learn skills to cope and constructively change negative thinking patterns and behaviours.
<https://www.camh.ca/en/health-info/mental-illness-andaddiction-index/dialectical-behaviour-therapy>

If you need counselling services, you may wish to look for therapists who are trained to help

Autistic people. You will be able to ask for the accommodations that you need while you receive services. Review the AIDE Canada “LOCATE” tool on our website, or you may seek for mental health support from your local Autism Services/Advocacy Office or mental health providers. For further help or resources, contact the Canadian Mental Health Association (<https://cmha.ca/>).

Isolation

Isolation is when a person feels separated from others. They can feel emotionally removed from a group or community. After receiving a diagnosis of autism, some individuals may feel alone and perhaps overwhelmed. Not knowing anyone else who is autistic can make a person feel like they are the only one in their situation. It is important for people to remember that there are Autistic individuals everywhere.

- **Reach out to groups, meetings, social activities, talks, podcasts, webinars, etc.** There is support in person and online. The community of autistic self-advocates and allies (non-autistic people supporting them) is growing every day. Being a member of this community can give you access to a huge network. For many, it is important to feel connected, and there are many groups online and in real life for which this can happen in the autism community.
- There are a lot of autistic people engaging in ‘self-advocacy’ work. Self-advocacy generally refers to asserting and celebrating the rights and personhood of autistic people and, when necessary, advocating for accommodations that empower them to live their best lives. There are many YouTube channels, blogs, or Facebook groups set up to help people feel a sense of community and gain a better understanding of themselves as autistic. **You belong and you are not alone!**
- **Consider getting a pet if you can and if you enjoy pets.** For many, pets have a beneficial impact on their mental health. People who are autistic are no different. There can be many emotional benefits associated with having a pet, such as easing depression, anxiety and stress. Having a pet provides a source of companionship and can help with feelings of loneliness. Just be sure that you plan for the cost and responsibility with owning a pet (e.g., food, treats, toys, grooming, veterinary care, etc). There are some helpful websites dedicated to calculating the cost of pet care.
- Another option to consider is an autism service dog. **Autism service dogs are professional service dogs that are trained to work with autistic people.** However, having a service dog is not cheap, but in some jurisdictions and circumstances, they could be funded by charitable programs. You will still need to be able to cover the costs of a non-service dog (e.g., vet care and food), but service dogs are highly trained and can assist with many aspects of your disability (e.g., help recognize when you are beginning to feel anxious and redirect your attention).

Disclosure

When you first receive news about your diagnosis, you might be tempted to let the whole world know. But before making that decision, take some time to think about it. Ask yourself if there are specific people in your life you want to tell. Having people who are close to you learn more about autism can be beneficial. Once they know more, they can offer support and can potentially help prevent social misunderstandings.

Disclosing to family and friends:

Decide who in your personal life you want to share the information with and whether you want them to keep it confidential or not. Keep in mind that once you share this information you will not be able to take it back. And there is no way to be sure this information stays private. **It is entirely up to you to decide who needs to know your diagnosis. You do not owe that information to anyone, if you decide to keep that information to yourself, that is also a valid decision.**

Some people are not sure how best to start the conversation with their family and friends. Please [click here](#) to access our article: "Disclosure: Tips and strategies for sharing your autism diagnosis with your loved ones"

Disclosing to your workplace:

Consider carefully with whom your diagnosis is shared or not shared when you apply for a job. If you are looking for work or have a new employer, sharing your autism diagnosis may prevent you from being hired. While it is illegal to refuse to hire you because you are autistic, an employer won't automatically get in trouble if they choose someone else who has the same qualifications. It can be very difficult to prove that the only reason they didn't hire you is because of your autism.

Some workplaces are specifically looking to support Autistic individuals and will say it in the job description. In those cases, sharing your diagnosis can help you get the job.

Carefully reading the job description, mission statement, inclusion policies, and employee reviews can help you figure out if this workplace is likely to support you and your needs if you share your diagnosis during the hiring process. If you are thinking about working for a certain company, conduct research to determine their inclusion policies.

If you think you may want to disclose your diagnosis to your workplace, please [click here](#) to read our article: "Disclosure: Tips and strategies for sharing your autism diagnosis at work"

How to respond when people deny your diagnosis

“You don’t look autistic to me”

Some people you tell may not respond in a supportive way when you share your diagnosis. It can be very upsetting for someone you care about to invalidate your experiences by saying that they don’t believe you are autistic. There are a few reasons that someone may not respond well:

- **People who do not understand autism well enough may make comparisons to autistic stereotypes they know from the media.** If their only knowledge of autism comes from TV, then it is not surprising that they may have a warped understanding of autism. Most of the time, people who don’t accept your diagnosis need more information about the autistic spectrum to reframe that knowledge. They may need more time to process the new information.
- **If you have been diagnosed with something else before, then people may still believe the previous diagnosis explains everything.** For example, if you were diagnosed with an anxiety disorder when you were younger, then they may have decided that all of your struggles are caused by that. Explaining that you can have anxiety and be autistic at the same time, and detailing how some of your experiences are not related to an anxiety disorder (for example, your sensory processing needs), may help people to come around.
- **People who have known you a long time may reject your diagnosis because they didn’t recognize that you needed support.** Especially with late diagnosis, people who have only known you one way might need time to adjust to the news of you being autistic. For parents or older family members, they may not want to accept your diagnosis because then they may feel guilty for not getting you the support you needed when you were younger. This is a “them” problem rather than a problem with who you are or what you shared about yourself.

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- For some of these parents or older family members who reject your diagnosis, they may feel like you are attacking them or judging them for not looking into getting you support before. **It may be helpful to discuss it in a way that makes it clear that you are not blaming, but instead are sharing new information that was not known when you were a kid.** You can help prevent this reaction by saying something like, “Mom, we know so much more about autism now than when I was a kid. Lots of people my age are being diagnosed as adults.” You can even share the link to our [“Research Summary: why more people weren’t diagnosed as children”](#) to show all the reasons that a diagnosis may have been missed if you think that would help them to not feel like you are blaming them
- **Some people may think you are using your diagnosis as an excuse.** They may think you are trying to get out of work or socializing and are just blaming it on being autistic. You can get ahead of this issue by sharing your reasons and offering examples of what you can do instead.

There is a difference between a reason and an excuse !

For example, let's say you are invited to the mall and you don't want to go

Your reason: It is loud, crowded, and overwhelms your senses.

The accusation: You are just making excuses because you are lazy or don't want to socialize. A helpful response: Point out that you are avoiding the setting, not the act of shopping itself. You can say you are willing to go shopping online or in a smaller store or offer to socialize in a quieter environment.

- **Ultimately, it does not matter whether they agree that you are autistic.** What matters is what you want them to do differently now that YOU have accepted that you are autistic. You can say, "Dad, I know you don't agree with the doctor that I am autistic. I, however, do accept that I am autistic. I am working on living the best life I can and finding out that I am autistic has helped me to make sense of some things. You don't have to agree, but I am asking that you support me as I process this and move forward."

Unfortunately, some people might never come around, but that doesn't mean that you can't move forward well. Know yourself, accept yourself, allow people to feel their feelings and come around when they are ready. **People's reactions are not your responsibility.**

Accommodations and support

Even if you have been able to lead your life without accommodations so far, you may want to look at options that may be available, such as resources at universities and colleges or in some workplaces. As an example, see the list of resources in Canadian colleges and universities on AIDE Canada's post-secondary resource Toolkits. There are various programs (some federal, some provincial, some privately funded) available to help autistic and other disabled people find employment. [Ready Willing and Able](#) and [Worktopia](#) are examples of national employability programs aiming at supporting Autistic individuals and people with intellectual disabilities to find gainful employment. Some employers, big and small, are collaborating with consultants to create inclusive workplaces. You may benefit from the help of a job coach trained to understand challenges specific to autism.

You may find additional resources on the AIDE Canada website or when contacting the local autism society.

As mentioned earlier, requesting accommodations may require that you disclose your diagnosis to your employer. If you formally have received a diagnosis, the individual or team who provided the diagnosis perhaps has provided, or can provide, documentation that may be helpful to justify needed accommodations. Also, your doctor could be asked to provide a letter requesting specific accommodations at work, without having to fully disclose to your employer. It is up to you to decide what would be the best option for you.

Funding programs are available for disabled people in need in Canada. Below are a few federal resources:

- Disability Tax Credit
- Persons with Disabilities Program
- Canada Pension Plan Disability Benefits
- Registered Disability Savings Plan

To learn more about these programs as well as other resources and services, review the AIDE Canada website or contact your local autism or intellectual disability service centre or society.

Acceptance

Receiving an autism diagnosis as an adult can trigger **complex emotions**. You may feel happy, relieved, angry, sad, or even nothing at all. The process is different for everyone. You may feel a sense of loss or go through a time of mourning. You might temporarily feel “more autistic” after your diagnosis.

To more fully accept the situation, it can be helpful to seek support from family and friends. You may also benefit from seeking professional help (see mental health section). It can also be helpful to speak with people who have had a similar experience. Exchanging your experiences, and feeling heard by someone who genuinely understands, can bring a sense of acceptance.

Lived experience is powerful and tells you that you are not alone. You can gain validation of your own experience and insight on how to talk to people about your diagnosis.

Just keep in mind that **a diagnosis is not the end but rather, the beginning of a new path.**

Conclusion

As discussed earlier, being autistic means you will experience challenges of variable intensity in certain areas, but also have abilities in others. **Once you identify your difficulties and strengths, start focusing on your strengths and rely on them more and more.** This is a key strategy to reframe your life positively post diagnosis. It allows you to create your own narrative about your life. Once again, asking for feedback from people who love and support you can help on that path.

AFTERWORD

We hope that this toolkit has provided you with some useful resources and tools to better navigate your life following your diagnosis. As previously mentioned, many people experience a wide range of emotions after being diagnosed as an adult and it

will take time to adjust to this new information and figure out the best way to incorporate it into your life. You may still struggle with some aspects of your diagnosis or with connecting with others, but you now have many more resources, tools, and supports available to you than before. Remember, you deserve to feel safe, comfortable, and happy. There is an entire community out there waiting to connect with you: You are not alone!

Autism is like a rainbow. It has a bright side and a darker side. But every shade is important and beautiful – Rosie Tennant Doran: Fellow Autist

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