

Strategies to Promote Well-Being

Snapshot

- Well-being has many different aspects and is influenced by internal, external and social factors.
- Self-care means making it a priority to do things that a person loves to do that make them feel better.
- Community care involves taking care of the needs of each other.
- We can learn self-care strategies to help us when we are feeling stressed or worn down by demands.
- Self-care planning involves building physical and emotional strategies into daily living to help deal with life challenges.

Well-being

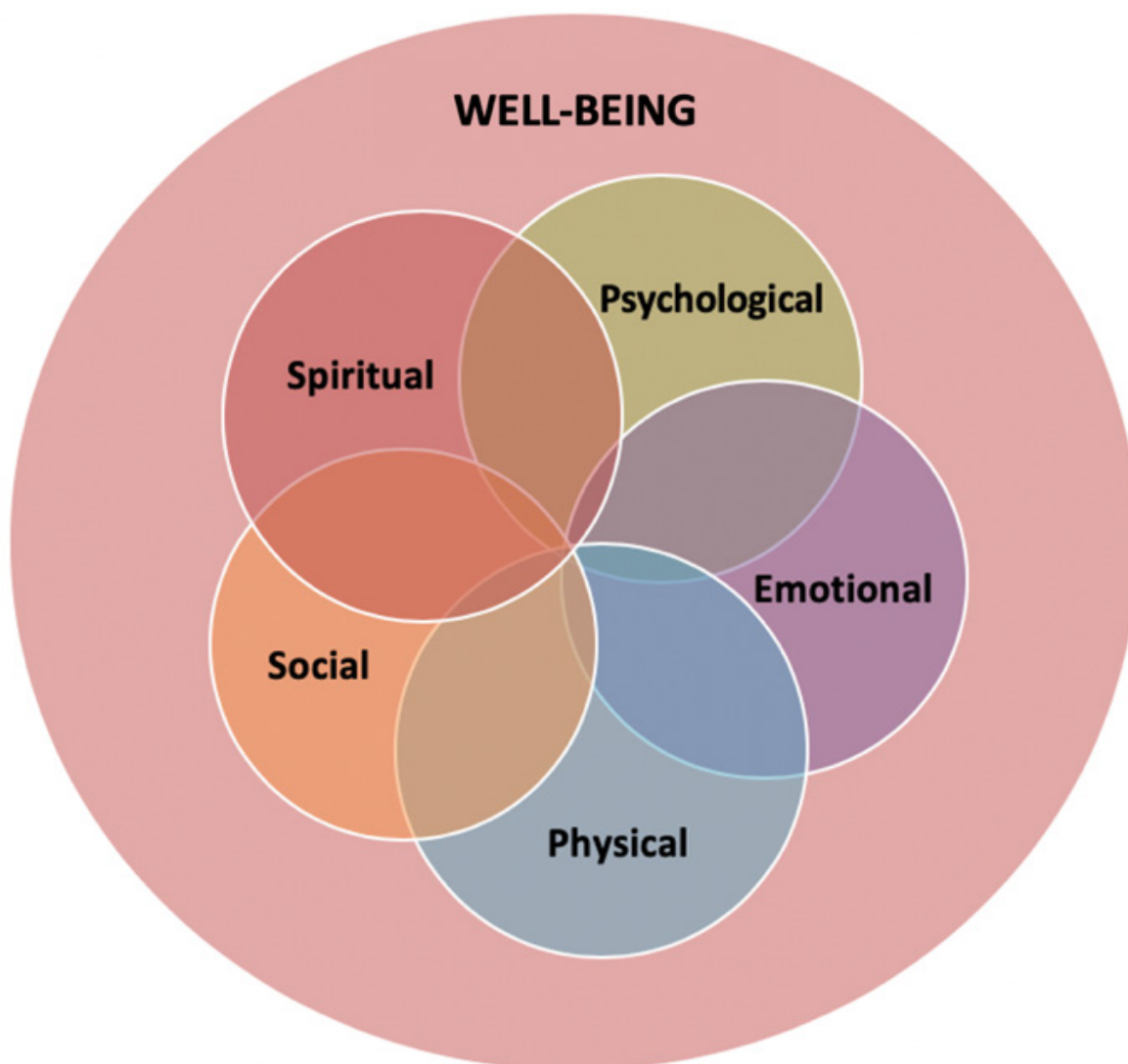
Well-being is a broad concept and has many different meanings. Well-being has been described as including “the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life, fulfilment and positive functioning.”¹

Well-being can be understood as how people feel and how they function, on both a personal and a social level, and how they make sense of their lives. There are different aspects of well-being, many of which may look like:

Well-being is based on how people feel and function, on both a personal and social level, and how they evaluate their lives. There are different aspects of well-being:

- psychological
- emotional
- physical
- social
- spiritual.

- **Psychological well-being²**
 - Self-acceptance (positive attitude about oneself)
 - Feeling of control over one's life
 - Ability to meet demands
 - Personal growth (knowledge about oneself or maturing; moving toward one's potential)
 - Sense of security in relationships with others
 - Confidence in one's skills
- **Emotional well-being³**
 - Being able to manage emotions
 - Being aware of emotions and understanding why they appear
 - Coping or adapting to stressors or problems
 - Managing stress and anxiety
- **Physical well-being⁴**
 - Feeling comfortable in one's own body
 - Being able to physically complete tasks (even if helped by aids)
 - Knowing the importance of, and doing, physical activity
 - Maintaining nutrition
 - Doing a variety of physical activities
 - Knowing when emotional stresses affect the body
- **Social well-being⁵**
 - Being connected to a community
 - Understanding how society works
 - Ability to make and keep friends
 - Having a personal network of support
 - Contributing to society
 - Feeling accepted in one's community
 - Seeing how society is going forward and how we can improve it
- **Spiritual well-being⁶**
 - Having a sense of purpose in the world (feeling that life has meaning)
 - Believing in something greater than oneself (e.g., nature or higher power)
 - Feelings of hope, faith or social connection



Well-being is a key element of a person’s overall quality of life. Well-being is something people strive toward—and it is very personal. **Well-being is different for each person day to day, and many factors can influence it.** External factors (such as community care, accessibility, housing, income and social connections) as well as internal resources (such as optimism, coping strategies or self-esteem) can affect well-being.

Autistic people, like everyone else, need friendship, support and opportunities to work and play in order to have a fulfilling life and to experience well-being. However, much of the time, these needs may not be met or be within reach.

Autistic experiences of well-being

“Autistic folks do have fun, we do build coping skills, we do have enjoyable things that make our lives worthwhile. Our lives are treated by society as being the worst-case scenario—like my birth was nothing to be celebrated. But that’s not true. I have fun; I have favourite toys/games, I like to draw and read, I look forward to comic book conventions, I love Christmas and Halloween . . . I have a full life. Not a tragedy.”

“No one else has reason to care about my well-being as much as myself. I'm a woman in my 40s who looks neurotypical but doesn't behave that way. I don't tend to get a positive response when asking for help or accommodation or asking a lot of questions unless I tell them my diagnosis of ASD. For some reason, the gender role expectations of a woman in her 40s these days is that I should be able to ‘handle it’ all by myself while juggling the demands of others, kids, a spouse and a full-time job, all while sleep-deprived.

“It is ridiculous what women are expected to manage every day inside and outside the home. I used to try to meet societal and role expectations and was very cruel to myself in the process. After my health reached a dangerous low, I was forced to stop trying to be ‘successful.’ I knew that if I was going to survive, I had to put myself first. I have learned that prioritizing self-care, self-compassion, non-comparison and developing an identity of my own that doesn't hinge on being something to someone else, are all ways that have helped me cope and find peace. Taking time to figure out ‘who is this person and what and how does she want to feel in this life and how can she best go about that?’”

Disclaimer: Some of these tips may not be relatable or accessible for all Autistic people, especially marginalized Autistic people, such as Autistic people of colour, Indigenous Autistic communities or the Autistic LGBTQIA2S+ community.

Knowing when to use self-care strategies

The “self” in ‘self-care’ reflects a focus on considering what we can do to help ourselves. It does *not* mean that a person excludes other people when caring for themselves. Self-care looks different for everyone and is not something that is always done in isolation. For some, self-care may mean connecting with others; that is, getting and giving support. For others, it may mean taking a break from connecting with others.

People may do self-care from time to time. **Self-care** is the many ways people can attend to their own needs, to keep themselves feeling as well as possible. Self-care can be important to maintain positive mental health, and to help when we are in distress or crisis.

Self-care are the ways people can attend to their own needs, to keep themselves feeling well.

Knowing you

An important part of self-care is knowing what a person’s **usual (or baseline)** is on a typical day (see **Section 5**). In thinking about what “usual” looks like for you, take note of how you are feeling in times when you are at your best self.

When a person understands their usual self and what is important to them in their day-to-day life, they are more likely to know when something is not right. This is a time when some self-care may help. It is also a time when a person can share about what they need with other people.

There are ways to help a person figure out their own usual. The national U.K. charity Ambitious about Autism created a toolkit for Autistic people to define their usual experiences, and record habits and feelings.⁸ It can be filled out any time

and can be used as a reference when sharing with others (such as family members, friends, teachers, co-workers/supervisors, service providers, etc.).

It describes brief baseline information about the individual completing the page with regard to the following (see Activity 6.1):

- An introduction to the person (e.g., name, age, a description or picture)
- Sleep routine—their usual waking and sleeping routine
- Relationships—how, when and with whom they usually spend their social time
- Interests and hobbies—their preferred leisure activities
- Staying Healthy—their preferred foods and physical activities
- Ways of looking after oneself—their usual hygiene routine
- Attitude and mood—their usual mood and feelings toward people and activities

Activity 6.1 – Knowing Your Own Usual^a

Follow this link to access Ambitious about Autism's "Know Your Normal" toolkit:

www.ambitiousaboutautism.org.uk/sites/default/files/toolkits/know-your-normal-toolkit-ambitious-about-autism.pdf

The toolkit explains how to fill it out and provides an example of a completed one for people to follow.

It can also be helpful to rate stress levels. One straightforward way to do this may be through the **Brief Distress Scale** (see Activity 6.2). This scale can quickly help a person understand where their stress levels are at or whether they are in crisis.⁹ This scale is like a distress thermometer. As a person's distress level goes up, that could be a good time to start self-care.

^a Please note the terminology change in the activity title from “normal” to “usual” as the AM-HeLP Group preferred less stigmatizing terms.

Activity 6.2 – Brief Distress Scale

On a scale from 1 to 10, rate where you are right now in terms of stress and crisis by picking one of the following statements:

Brief Distress Scale Adapted from the Brief Family Distress Scale ⁹	
1	– Everything is fine, I am not in crisis at all.
2	– Everything is fine, but sometimes I have my difficulties.
3	– Things are sometimes stressful, but I can deal with problems if they arise.
4	– Things are often stressful, but I am managing to deal with problems when they arise.
5	– Things are very stressful, but I am getting by with a lot of effort.
6	– I have to work extremely hard every moment of every day to avoid having a crisis.
7	– I won't be able to handle things; If one more thing goes wrong – I will be in crisis.
8	– I am currently in crisis, but I am dealing with it myself.
9	– I am currently in crisis, and have asked for help from crisis services (community crisis supports, hospital, emergency room, etc.)
10	– I am currently in crisis, and it could not get any worse.

Autistic experiences with self-care

“Self-care was—and is—always important for me. The realization that no one was going to come and take care of things for me meant that I had to start doing what was best for me anxiety-wise from a young age. The teacher in our class isn't going to hold my hand when a panic attack rolls through—that's not their job. The professor isn't going to sit with me while my meds kick in. The principal isn't going to fight this anxiety attack for me—not only because they physically can't, but also because they don't care to. So, if I get up and leave the class, that's what I need to do for me. If I need to go for a walk, if I need to decide I can't come in to the lesson today, that's what's happening. And if the professor or the principal or whoever doesn't like it, they have two choices: I can have this episode in their class and it will be uncomfortable for everyone involved, or I can quietly get up, go for a walk and maybe come back when I've come down from it. They are not my priority. My first loyalty is to myself.”

“I find it exceptionally hard to know I need help or ask for help when I need it. Like many Autistics, I am supremely sensitive to judgments and negative feedback and have the irrational notion that asking for help will diminish my stature in the eyes of family and work colleagues. As well, when I try to do self-care, a family member is inevitably asking for my help. I cannot get that quiet ‘alone’ time to read a book, have a bubble bath or browse antique markets. Families can be great; they can also talk the talk but not walk the walk. It’s like, ‘I know you’re Autistic—now don’t be, because I need you to babysit all weekend.’ Self-care is a self-indulgent concept in my life, one that is not necessarily well-tolerated. I love my family, so it seems a small price to pay for peace.”

“When dealing with a highly stressful situation or problem, the last thing on my mind is self-care. When I am going through hell, the only way out is to keep going. I need to solve the dilemma, come up with a plan and figure it out. The planning and problem-solving, for me, improve my well-being.”

“I choose to find value in crafting, sewing, gardening and home improvements—all activities that are home-based. And I only shop locally, a short walk from home . . . I prioritize family and friends and have people over for tea in the garden or BBQs in good weather. Music and art, reading and learning are all positive activities that can be fulfilled over the internet. I enjoy teaching and offer sewing and crafting on a one-to-one basis. My life is balanced and fulfilling.”

“I try not to be too hard on myself. I allow myself to hear and respond to things the way my mind naturally wants to. If I’m in the middle of a conversation and I’m focused on what another person is saying, I may look away as a butterfly moves past or a bird comes into focus on a nearby tree. Having a partner who accepts this is important for me and for our relationship. I’ve always been very easily distracted. I’ve constructed my world so that there are no other people around me most of the time, and a lot of space (no houses or any neighbours within sound or sight). This way, I can work on projects at the whim of my mind. If it wanders, I wander with it.”

“Long-term strategies for well-being for me include long-term plans. Working out four to five days a week has been a long-term strategy of mine. It has been consistently there to help with mental health and focus and having a clear mind. Long-term goals for me include upgrades to my shop and equipment used. For example, certain increases in modernizing equipment in fiscal year spending plans.”

Community care

The idea of self-care often assumes that every person has the ability to perform self-care, has access to supports and makes use of them. However, self-care can be hard to do and, in many cases, it may not be possible because of external factors (such as stigma or isolation) and societal barriers (such as accessibility limitations). This gap is especially present in some disabled communities where their limitations and needs for care are ignored. By only talking about self-care, this takes the responsibility of care away from the community and places it on the person who requires the help. Part of well-being is understanding our connection to our communities.

Community care is choosing to take care of each other, including oneself and others in the community.¹⁰ This perspective of care is inclusive and works interdependently (which

means people depend on each other) within a cooperative community. It is a type of self-care where people take part in helping and caring in ways that help the community as a whole. Examples of community care are peer support groups, informal networks and “spoon shares” or neighbourhood “pods.”

Mutual aid is when we provide social support or resources to each other, like running errands for someone in need or giving food to people when they cannot afford it. It involves providing voluntary support to people who share a common experience.¹¹ These groups work to meet each other’s needs to survive. They use resources from their community.

Like mutual aid, spoon shares and pods give support as a part of community care. **Spoon shares** are groups that connect people needing short-term or long-term help due to injury, illness, disability or other life challenges.¹¹ **Pods** are made up of people in the neighbourhood or family that a person would go to in case of an emergency (see Activity 6.3).

Community care is choosing to take care of each other (one’s self and others in their community).

Mutual aid involves providing voluntary support to people who share a common experience.

Spoon shares are groups that connect people needing short- and long-term help because of injury, illness disability or other life challenges.

Pods are neighbourhood groups made up of people working to get everyone’s needs met.

Community care can have some challenges. Offering, asking, receiving or declining help may not come easily to an Autistic person. This can be even more challenging when someone struggles with mental health challenges. These social-communication-based actions may be scary, hard or triggering for the Autistic person. However, community care functions on the basis of support and understanding. A person doesn't have to get it right the first time.

“Community care improves well-being just as much, if not more, than self-care. Over-emphasis on self-care is one of the ways society fails at securing the well-being of disabled people.”

Activity 6.3 – Pod Mapping

The *Bay Area Transformative Justice Collective* (2020) created a “Pods and Pod Mapping” worksheet to help people start the process of identifying who could be in their pods.¹² You can find the worksheet at this link:

<https://batjc.wordpress.com/pods-and-pod-mapping-worksheet/>

Community care supports

With online access, community care can reach many people. Group forums, such as those that can be found on Facebook, as well as group chats through various phone apps are just some of the tools that have been used to take part in community care.

It may be difficult to find the right group chat or online forum. Following are some suggested questions to consider when searching for one, as shared by some of our advisers:

- Are the posts on this forum/group chat largely positive? Or negative?
- Is there a lot of fighting or arguing between people on this page/group chat?
- Does the page/group chat have rules about no homophobia/transphobia/racism/sexism, etc.?
- Do I feel happy having been on the page/group chat or am I tired, frustrated or angry when I sign off?

Below are some common resources that can be given or asked for in community care situations:

Common Community Care Resources	
Practical	<ul style="list-style-type: none"> • Household chores (e.g., cleaning, cooking) • Personal hygiene (e.g., buying shampoo, hair cutting) • Equipment or supplies (e.g., laptop, office supplies)
Travel	<ul style="list-style-type: none"> • Rides to appointments or grocery stores • Walking escorts
Relief	<ul style="list-style-type: none"> • Respite (e.g., child or pet care) • Encouragement, support or advice
Share	<ul style="list-style-type: none"> • Sharing resources (e.g., job postings) • Sharing lived experiences
Service	<ul style="list-style-type: none"> • Recommendations for low-income housing or LGBTQIA2S+ friendly services • Help with completing forms or taxes

In times of emergencies or crises, communities need to work together and care for each other. For disabled people, their lives may have more frequent emergencies and crises than non-disabled people.

Autistic experiences with community care

“The best thing that I have found to support me, is community. The autism community understands Autistic people. I run several online support and community groups, and it is those communities where I have found the best advice. The spectrum is huge, so if one group isn't a good fit, another will be. Autistic people online (there are few in-person groups) are a great resource. A lot of mental health issues are a result of isolation from other Autistics, so meeting up online, sharing experiences and sharing coping skills really has a positive influence on self-esteem. Knowing you are heard, understood and supported by others *like you* is the best.”

“For me, I find national and regional Autistic-led support groups to be immensely helpful to ask for local and regional resources, because there’s virtually always someone who has sought the same support that I am seeking, and they tend to have the best recommendations for who and what is helpful and what is not. These groups have saved me from waiting on wait-lists for things that aren’t actually helpful in the end, many times. They’ve also provided names and programs to be referred to that my doctors haven’t even been aware of.

“I would like to share that one of my biggest and most successful self-care strategies is asking for help. I pose questions to similarly affected individuals and I ask for advice on how they’ve solved the same problems I’m dealing with. Hearing from other people who are like me and who have shared lived experience is one of the most hopeful and helpful parts of self-care that I do for myself. It makes me feel like I’m not alone. It also helps me to organize to remove these problems and barriers for others, and that helps me to cope.

Societal support of Autistic well-being

Asking for help is considered a sign of strength and maturity, and a sign of heightened self-awareness. Non-Autistic people ask for help as well—it is not just something that Autistic people do. There is a lot that society can do to improve Autistic mental health and well-being. It is not up to the Autistic person alone to understand well-being. To feel capable and successful, Autistic adults may need some supports in their environments: at home, at school, at work, at volunteer places and more. This section talks about what Autistic people may need.

Universal design

The best way society can change is to make things more universally accessible as much as possible, so people do not have to constantly request for individual accommodations. Ideally, environments should be built for all kinds of people from the start, and then adjustments should only be needed for any remaining gaps or barriers.

Universal design is the creation and design of products and environments that allow everyone with all levels of ability to access, understand, use and participate in society. It includes the following aspects:

Universal design is the creation and design of products and environments that allow everyone to access, understand, use and participate in society.

- **Physical accessibility**¹³

The design is accommodating, comfortable and useful for a wide range of physical disabilities. Some examples include:

- main entrances that have wheelchair-accessible ramps and automatic doors
- accessible elevators at the workplace
- signs with braille that say the names and numbers of rooms or buildings
- rooms with enough space for wheelchair users.

- **Sensory accessibility**¹³

The design is safe and provides critical information effectively, regardless of sensory abilities. Some examples include:

- available hearing aids (sound devices, microphones) or noise-cancelling earmuffs
- available visual aids (e.g., closed captioning or image descriptions)
- available American Sign Language interpreter
- safe place that does not trigger people with chemical and light allergies and sensitivities
- nut-free policies
- fragrance-free policies.

- **Cognitive accessibility**¹³

The design is easy to understand, regardless of the person's experience, language, knowledge and concentration level. Some examples include:

- making a schedule and sending it to people in advance
- providing options for accommodation requests
- using name tags and colour communication badges to support social interaction
- allowing for space and time to take breaks
- providing information in plain language
- offering alternatives to interviews for hiring, such as demonstration tasks, walking interviews, supplying interview questions in advance and allowing written responses.

Supports for Autistic people

Specific supports will vary according to the person, but it is important to have a community-based approach when supplying supports for Autistic people. It takes a combination of understanding autism, having respectful community support (Autistic adults, service providers and family members working together – not separately) and allowing for individual adjustments for Autistic adults to thrive. One idea an adviser suggested is to “bring in an autism educator and trainer to educate management and staff on accommodations and antibullying policies and practices.”

Possible supports and accommodations	
Environments	<p>Making the environments more inclusive. For example:</p> <ul style="list-style-type: none"> • Smaller meeting sizes are ideal, as it can be easier and less overwhelming for Autistic people. • Allow more personal space in meetings and in workspaces (e.g., private cubicles or office with a door) to lower nearby stimulation. • Allow fidget materials. • Allow the use of ear plugs or headphones, or sunglasses to block the sensory input. • Provide or modify equipment (e.g., adjustable desks). • Use visual aids. • Allow plants and therapy pets to soothe stress. • Use less fluorescent lighting. • Provide access via elevators. • Provide gender-neutral and wheelchair-accessible washrooms. • Create a quiet space (designated spaces where anyone can go to recharge). • Provide private work spaces. • Provide on-site job coaching that includes teaching the hidden curriculum of the workplace.
Schedules	<p>Having clear schedules and predictable transitions aided by multiple cues (visual and audio). For example:</p> <ul style="list-style-type: none"> • Prioritize tasks and give a defined deadline for completion. • Give breaks. • Have fixed routines. • Be flexible with routines. • Allow modification in schedules. • Allow extra time to complete work. • Offer longer or shorter sessions. • Offer flexible work hours or options to work from home.

<p>Tasks</p>	<p>Restructuring tasks to provide opportunities to do, present or communicate in an Autistic person's preferred way. For example:</p> <ul style="list-style-type: none"> • Provide extra training or one-on-one time. • Provide the choice of self-recorded presentations. • Provide options to opt out of group presentations. • Encourage different ways of interviewing for a job.
<p>Support services</p>	<p>Providing qualified assistants or support services. For example:</p> <ul style="list-style-type: none"> • It can be helpful for an Autistic person to have access to an experienced advocate or mentor, who can help with navigating and potentially finding solutions to being in different environments.
<p>Communication supports</p>	<p>Offering different ways of communicating. Some Autistic people do not like phone calls, not just because of the sensory difficulties, but it may also be hard for them to start conversations, know when to speak and know what to say. At times, some Autistic people may need tools such as augmentative and alternative communication (ACC). AAC includes communication devices, systems, strategies and other tools to replace or support speech. For example:</p> <ul style="list-style-type: none"> • Provide repetition for cognitive processing. • Provide communication badges. • Allow for multimodal communication (there are lots of AAC devices that do this). • Provide different ways of communicating (e.g., email, videoconference, social media, text). • Keep instructions clear and concise; use unambiguous language.

Ways to support Autistic people

Autistic acceptance

Autistic acceptance is the acceptance of autism and Autistic differences and recognizing that Autistic people have the right to be and to live their authentic selves. This requires work from the non-Autistic community to recognize their own biases and to acknowledge that all Autistic people are their own person. Acceptance includes understanding that autism is diverse and embracing it. It involves making Autistic voices heard and understanding that they are experts of their lived experiences.

Autistic acceptance is the acceptance of autism and Autistic differences and recognizing that people have the right to be and to live their authentic selves.

“Societal support is limited in many ways, such as mental health and understanding in certain groups. Even Autistic government-funded groups at times do not have us included as voices as the main stakeholders. This is extremely detrimental to the accuracy of what these groups and government funding can do to help the body of people they say they represent.”

“Society often puts the onus on Autistic or otherwise-disabled people to ‘do better’ or ‘get better’ or ‘fit’ and less on what society can do to help people in the community. It’s rather like bridge-building. Both sides need to work hard—I can only build a bridge halfway, but if I see that people on the other side (the non-Autistic community) aren’t working hard, then why should I work hard for them? What am I building a bridge for? I can’t build the whole thing myself.”

Reassurance

Reassuring the Autistic person that there are no invalid or ridiculous questions, and that it is okay to ask for clarification or more details, can be very helpful.

Helping or encouraging a person to clarify what needs to happen, when and how, and helping them write up their own plan, can be empowering.

Patience

If an Autistic person is struggling, it is also useful to help them think about what aspects of the situation they can control, what they can’t control and if there’s anything they can do to feel more in control. This might be anything from deciding on an end time for an event to learning to better identify what their stressors might be and having a plan for how to counter them.

If you are with an Autistic person experiencing a meltdown, do not crowd them or overwhelm them with questions and concerns. Be calm and reassuring; let them take their time and listen to what they might need. One Autistic adviser said: “I find being offered water very helpful. So, asking beforehand if an Autistic person has instructions in case of meltdowns, or maybe even a card (instruction) or MedicAlert bracelet.” These may be very useful for some Autistic people but may be inappropriate for others.

Some Autistic people may not be able to communicate verbally when in distress, even if they are usually very articulate. If necessary and possible, help them get to a safe and quiet place away from things like bright lights, loud noises and other people.

Connecting

It can also help for non-Autistic people in an Autistic person's life to try to connect with them based on their interests, and on their terms. **Socializing may be exhausting for many Autistic people, when they must mask and worry about non-Autistic expectations**, but socializing may still be wanted. Therefore, it's important that the person can feel safe in being allowed to be themselves, to define their own boundaries and to say when they need alone time.

Many Autistic people spend a lot of their lives masking to fit in socially or putting extra energy into navigating a non-Autistic social situation. It can be very helpful for non-Autistic people to try to learn ways to make it safe for Autistic people to remove the mask and exist as their authentic Autistic selves. It is good to be direct about social expectations and boundaries, as well as being honest and openly reassuring about common concerns, such as being excluded or isolated.

"I am immensely grateful for the social networks of my family and friends that I do have. I may not have or ever have the biggest social network as my life continues, but right now I do feel that there is always at least one person in my current network that I can talk to and/or get tips from on serious or positive thoughts I'm having. My social relationships are all on a basis of respect and partnership."

Advocating with Autistic adults

It can also help when non-Autistic people **advocate with Autistic adults**. This means helping an Autistic person to express their needs, protect their rights, represent their interests and access services they may need. As one adviser said: "I think the most important thing to keep in mind for a non-Autistic in advocating for Autistics is to elevate the voices of Autistics rather than speaking over them."

It is important to know when advocacy is the right thing to do. **Being a good ally means knowing when to pass the microphone on to the Autistic person and empowering them to use it.** Non-Autistic advocates should be careful not to advocate for what they believe the Autistic person needs, and instead focus on what the Autistic person is expressing that they need.

Being an Autistic ally can include the following qualities¹²:

- understanding autism and/or mental health
- challenging ableist attitudes in environments that may continue to be biased against Autistic people
- asking the Autistic person what type of support they need
- building trust with Autistic people
- having patience and accountability in working together with Autistic people
- showing assertiveness in representing Autistic people
- having a willingness to learn about Autistic people's rights, advocacy and activism history
- viewing advocacy as a partnership with Autistic people
- supporting Autistic self-advocacy.

Autistic experiences with finding supports in society

“Writing up your own plan, or writing with assistance, is so important. Many of the parents and schools I’ve talked to do not have the student involved in the writing of their IEP (individual education plan), and it’s infuriating that a learning plan is made up in the absence of the learner. Especially as everyone says they want that Autistic/disabled person to become independent—but then divorce them from empowering decision-making that is directly about them! Put the individual back in the individual education plan.

“Often, disabled people in general are treated as too stupid to know what’s best for us. By giving that person a voice back, a chance to say ‘I do know what’s best’ or ‘I have some ideas about how I want things to go’ returns agency and power back to that person. Too often, stuff is done for us in our absence because ‘It’s just faster this way’ or ‘They don’t know what’s best anyhow.’ It’s insulting.”

“When my sons were of legal age and they first went to a nightclub/bar, there was loud music and strobe lights on. It was very interesting when the person they were with asked the waitress if maybe the music could be turned down a bit and the lights up a bit, as no one was really there yet. The waitress looked at him a bit odd and then said: ‘Sure, till it gets busier, no worries.’ She could have said no, but having someone along to show it never hurts to ask has helped my boys to know it’s okay to self-advocate for themselves, too.”

“Attending an Autistic-led conference for the first time was an eye-opener for me. With supports ready and waiting to be accessed and the day planned out to be less intimidating and more supportive, I couldn’t believe the difference in experience at this autism conference. The seminars were calmly lit, the sound levels low (with FM system, sign language and easy-to-read handouts available for those who needed them), the PowerPoints well-written and not overstuffed so as to be easy to follow, the Snoezelen room, the break room . . .”

Short-term self-care strategies

Short-term strategies mean that these strategies can be done whenever a person wants in order to immediately boost well-being. These strategies are sometimes called **“quick wins.”** But these quick wins can combine together to have a big benefit (see Activity 6.4). If a person does not care for themselves in the short term, it may affect their well-being over time.

Short-term strategies (also known as “quick wins”) mean strategies that can be done whenever a person wants in order to get an immediate boost of well-being.

Short-term strategies are unique to each person, and it can change depending on the day or time, who is around them and other factors. What may be fun or pleasurable for one person may not be fun or pleasurable for another. Below are just some of the short-term strategies Autistic adults have used for a “quick win.”

Short-term (“quick win”) strategies	
Psychological	<p>These activities involve nurturing one’s sense of growth or accomplishment:</p> <ul style="list-style-type: none"> • Focusing on passions and intense interests • Planning and problem-solving • Writing • Asking questions (e.g., being curious, investigating or researching topics) • Eating comfort food (e.g., chocolate or candy) • Enjoying music (e.g., listening to favourite sounds or songs) • Learning a skill (e.g., woodworking, knitting) • Doing something creative (e.g., painting, drawing) • Getting chores done • Giving oneself permission to feel upset and frustrated, and permission to overcome these feelings • Thinking about things that give feelings of happiness, calmness, comfort and safety • Looking for or holding on to a comfort item (e.g., stuffed animal)
Physical	<p>These activities involve movement:</p> <ul style="list-style-type: none"> • Stimming (i.e., self-stimulatory behaviour, from rocking and stroking certain textures to watching colourful lights or fidgeting with an object) • Structuring days to include fun activities • Eating • Sleeping • Laughing • Sitting or swinging on a hammock or swing • Walking, running • Gardening • Dancing • Listening to music or singing • Enjoying the beauty of nature (e.g., going for a walk) • Taking a long hot or cold shower • Having consensual sex • Masturbating • Doing yoga • Working out • Taking medication that helps
Social	<p>These activities involve connecting with others:</p> <ul style="list-style-type: none"> • Playing with or hugging a pet • Talking to a trusted/safe person or close friend • Getting together with family or friends or interest groups • Meeting online with other Autistic adults or neurosiblings (other people with different disabilities) • Joining online and in-person communities • Watching a favourite TV show or movie with others • Taking a break from socializing • Playing games • Going to the gym or the bar

<p>Environmental</p>	<p>These activities involve reducing outside factors or sensory overload:</p> <ul style="list-style-type: none"> • Laying on a sensory surface that’s appealing to the person (e.g., grass) • Going to a sensory room • Going to a quiet room with dim lighting • Using noise-cancelling headphones or earplugs • Listening to soothing sounds • Touching soothing textures • Putting on sunglasses or a hat to block out lights • Using a weighted blanket • Going swimming • Napping • Problem-solving to overcome barriers
<p>Spiritual</p>	<p>These activities involve doing things that bring a person closer to their beliefs and/ or a sense of purpose that can help guide or comfort them:</p> <ul style="list-style-type: none"> • Meditating • Practicing yoga or martial arts • Praying • Being in nature • Reading spiritual or religious texts • Connecting with a spiritual or religious community • Meeting with a mentor, Elder or religious elder

Activity 6.4 – Quick Wins

Strengths: One quick win involves recognizing your strengths. Think about five of your greatest strengths (e.g., your sense of humour, the way you think, your skills). List them below.

1. _____
2. _____
3. _____
4. _____
5. _____

Role models: Another quick win can involve identifying role models (famous or not). These could be other people who have overcome adversity in life and whom you admire because of the way they take care of themselves, both in calm and in challenging periods. Think specifically about why you are choosing these particular role models and identify the characteristics that you appreciate them in.

Role model: _____

Why did you choose this person? _____

Role model: _____

Why did you choose this person? - _____

Autistic experiences with short-term self-care strategies

“I have a self-care shoebox where I put in a few small candy bars, some video games and movies, fidget toys and the like. Or at times I say to myself, ‘How can I relax today?’ and make a list of activities I would find enjoyable and pick a few from the list.”

“One of the really therapeutic things I’ve learned is that, although I may not connect socially with other people very much or very often, I can still exercise that muscle of back-and-forth interaction or relating with something outside of myself in different ways—like by singing along in harmony with a song. I’m interacting with it, keeping in time with the rhythm, improvising harmonies, tuning in to the emotional feelings of the music, expressing myself in relation to it. This all takes focus and timing and involves my own initiation of input and response in some way. Or dancing to music or playing an instrument along to music is another way to interact with music.

“At the end of it, I feel like I’ve just had a conversation but without experiencing the stress of being misunderstood, judged or criticized that usually comes with interacting with people. It’s cathartic and feels good. To me, it feels like a healthy and safe way to express myself, interact, connect and relate.”

“I have recently rediscovered how important the physical act of writing is to me. I do a variety of self-care activities in my spare time, as mentioned earlier, such as word searches (which are a great mental jogger for me in coming up with my own pun jokes), mandala colouring books, seeing my favourite TV shows and movies, socializing (e.g., going for a cup of coffee, out to lunch with at least one friend), walking, reading and the gym. I also like writing, too. However, I had not been physically writing for months and I did not realize how important this physical short-term strategy is for my own self-care. Now that I have started putting pen to paper again in this journal brand called *The Five-Minute Journal*, I’ve been feeling an internal lightness that I had not felt in a long time. So, now I consciously know that I need to more regularly add writing to my personal arsenal of self-care strategies.”

1. Check-ins about the basics

Part of self-care is noticing what is happening to the body and mind (see Activity 6.5). When situations or thoughts are very stressful or overwhelming, it may be helpful for Autistic adults to take their time to check in with activities that can help to take care of the body and mind.

Activity 6.5 – Check-in Questions

One quick way to check in is to use the HALT acronym and ask yourself:
Are you hungry, angry, lonely or tired?

Below are further questions to ask yourself daily to check your usual:

- Did I have something to eat or drink?
- Did I sleep?
- What am I feeling today?
- What is occupying my thoughts today?
- Have I had time to go outside?
- Have I had time to go for a walk, if possible?
- Have I washed, showered or cleaned up?

It is not always easy to understand why a person is feeling certain ways. It can be difficult for some Autistic adults to recognize or tune in to their body's distress signals. For example, sensory differences may make it difficult to identify whether an Autistic person is experiencing low mood, irritability, hunger or pain. They might feel angry, but once they eat, they feel better. As one adviser said, "Alexithymia makes it incredibly difficult to process how I'm feeling at any given time. It takes time and concerted effort and certainly not something I'm able to do as a quick check-in."

Activity 6.6 below can be used as a tool to check in with well-being. When days are full of stressors, it can be hard to see how well usual needs are met.

Activity 6.6 – Interactive Self-Care Flowchart⁸

This interactive game called **You Feel Like Shit: An Interactive Self-Care Guide**, created by Jace Harr (2015), is an easy and helpful chart for people who struggle with learning how to recognize their inner signals and for those who may not be good at looking after themselves.¹⁴ Follow this link to access the game:

https://philome.la/jace_harr/you-feel-like-shit-an-interactive-self-care-guide/play/index.html.

2. Self-compassion

Self-compassion is about taking a gentle approach with oneself in the moment. It involves recognizing and appreciating personal strengths and being kind to ourselves. It is also being content with who you are. This can take a lot of practice (see Activity 6.7). Autistic people can be particularly hard on themselves and may hyper-focus on small mistakes, social mistakes and things they should have done. They can start to focus on what they think they are doing wrong, instead of all the things they are doing right.

Self-compassion is about taking a gentle approach with oneself in the moment.

Acknowledging your strengths and giving yourself the permission to be imperfect may involve learning to think in new ways about situations. For example, acknowledging positive aspects about oneself— such as a good sense of humour, perseverance, motivation, physical or verbal abilities—is particularly important when a person is stressed. This can improve self-esteem, self-worth and mental health.

Dr. Kristin Neff (www.self-compassion.org) describes self-compassion as three processes:

1. **Self-kindness**: Being understanding to oneself when feeling inadequate or that one has failed or is struggling.
2. **Common humanity**: Recognizing that being imperfect is okay and that people are affected by many factors outside of themselves.

3. **Mindfulness**^b: Being aware of one's thoughts and feelings, in a non-judgmental way.

Activity 6.7 – Gauge Your Self-Compassion

Dr. Neff suggests asking yourself the following questions to gauge your self-compassion:

- How do you typically react to yourself?
- What types of things do you typically judge and criticize yourself for (appearance, academics, relationships, etc.)?
- What type of language do you use with yourself when you notice some flaw or you make a mistake? Do you insult yourself or do you take a kinder and more understanding tone?
- When you are being highly self-critical, how does this make you feel inside?
- When you notice something about yourself you don't like, do you tend to feel cut off from others or do you feel connected with your fellow humans who are also imperfect?
- What are the consequences of being so hard on yourself? Does it make you more motivated and happier, or discouraged and depressed?
- How do you think you would feel if you could truly love and accept yourself exactly as you are? Does this possibility scare you, give you hope, or both?
- How do you typically react to life difficulties?

^b The practice of mindfulness originates from Buddhism and the early teaching of the Buddha. It was popularized for therapeutic purposes in Western society by Jon Kabat-Zinn (1990).

3. Positive self-talk

One way to think about difficult situations in new ways is using **positive self-talk**. It may be helpful to talk yourself through situations that can be stressful or complicated with a positive mindset. For example, a person may tell themselves: “I am doing the very best I can. I’m only human. I am caring and loving.” Letting yourself experience emotions is important when coping with difficult circumstances. Sometimes it may not be appropriate to speak out loud, but a person can think these thoughts or write them down.

Positive self-talk means talking to yourself through situations that are stressful or challenging with a positive mindset.

Autistic experiences with short-term strategies

“‘Taking a break’ and ‘pampering’ yourself by dressing up or going for something like a makeover, shopping, etc.: all the things the other women listed for ‘coping strategies’ were the opposite of what calms my nerves and senses. My answer for ‘coping’ was to focus on the issue at hand, go over every detail and connections until I’ve pulled together some understanding and solution moving forward—then I get that release from the anxiety. But taking breaks from it will just make me more anxious. I need to study it, dissect it and make sense of it, then I’ll feel better. No bubble bath or pedicure is going to help me feel better. It will only add more unfamiliar and/or superfluous sensory input that increases the overwhelm and overload . . . Reducing stimuli and being allowed to ruminate, dissect, find connections and create possible solution options helps me get through the anxiety to the other side of relief.”

“Getting it done if something needs doing or sorting and analyzing information to figure out what/where I went wrong is the only solution to stress for me. If the problem is within myself, then I examine myself (hopefully fairly, not harshly), and then I can decide whether I had any control, any responsibility, for the outcome. If the answer is no, I did not have power over or control of what happened, then I am not responsible.”

“Using visualizations has really helped me to deal with my anxiety and monitor myself. By coding my anxiety I’ve found ways to say, ‘I can handle this’ or ‘I need to leave this situation.’ And sometimes having a plan in place to handle anxiety makes me feel safer or able to stick with a situation longer.”

“I know some Autistic adults who avoid doing things that provide comfort and pleasure because they are scared it will make them look like a child. They have been shamed for it in the past. Things like carrying a stuffed animal around, thumb-sucking, even rocking back and forth and fidgeting. Without going into how shaming people for looking like children also demeans children, Autistic people should not be shamed for self-care. Engaging in self-care is a sign of maturity and growth. It means understanding and doing things to care for oneself. As we grow up, we regress in that understanding. It’s why there is this whole self-care movement to learn it all over again. I’m a budding researcher, an organizer and a changemaker—and I carry a stuffed animal with me. Get used to it.”

Long-term self-care strategies

1. Recognize and address challenges

When experiencing many challenges, it may be helpful to try to identify and prioritize them. It may prevent a person from feeling overwhelmed and can help set them up to be more successful. It is not always easy to prioritize needs.

Sometimes, a person struggling to improve well-being or mental health looks to others to “fix” the problem or may want to get rid of it completely. Sometimes this is possible. Some challenges cannot be fixed quickly or easily though. Sometimes, changing how we think about the problem or the ways of coping with the problem may be helpful instead (see Activity 6.8). A person can learn ways of coping with the problem, to move forward and thrive despite it, instead of believing they must get rid of it from their lives entirely.

Activity - 6.8 Worksheets on challenging thoughts and coping

Courtney Ackerman's Positive Psychology blog (2020) provides many useful worksheets to use in the long term and is a useful resource:

- For help dealing with challenging thoughts, read the ideas suggested in these blogs: <https://positivepsychology.com/blog/>
- If you're interested in other coping worksheets, you'll find more here: <https://positivepsychology.com/coping-skills-worksheets/>

2. Set boundaries

Boundaries are rules and limits that a person sets for how others should treat them safely and respectfully. Personal boundaries allow people to feel comfortable in their space. It ensures that the relationships between people are respectful, appropriate and caring. Some boundaries are simple, and others are complex.

Boundaries are rules and limits that a person sets for how others should treat them respectfully and safely.

For some people, if boundaries are not set, situations may be confusing and can lead to frustrations and challenges in relationships and friendships. Being clear on boundaries can keep people safe and may reduce the chances of relationships or interactions that are hurtful or harmful. Boundaries can help to keep a person safe from people who would take advantage of them (psychological, physically or financially).

Both Autistic and non-Autistic people can find setting boundaries very difficult. Setting boundaries can be distressing in the beginning. For example, a person may not know when to communicate, they may think they are overreacting or they may not want to upset the other person. Autistic people may have had experiences, including of past interventions, where they were taught to suppress their natural way of expressing their boundaries. Relearning how to express boundaries in a way that works for them is a process and can take time.

“I have difficulty with boundaries and saying no to people. I tend to just go along with things, even if it’s not what I want or if I’m scared or uncomfortable. I’m not sure if it stems from being expected to put up with bad sensory situations (being told to grin and bear it, not to show people that I’m in pain or upset when loud noises happen), being yelled at for asking for help/social anxiety or having to face down fear due to my anxiety.”

“When talking to close friends and family, I say, ‘I am not always good at knowing how I come across, so if you don’t tell me, I can’t know, so you can’t hold it against me.’ That way, I can be me and not *always* try to be perfect in tone, volume, conversation turn-taking, eye contact, etc., as sometimes I am just too tired to try. This is me saying: ‘Sometimes I just need to be me, so if you can accept that and not try to change me, that would be great.’ Which I also say to people.”

Samantha Craft (a.k.a. Marcelle Ciampi), Autistic author and senior manager of diversity, equity and inclusion at Ultronauts Inc., wrote about boundaries and advised on how to set them in her blog, *Everyday Autistic*, and we provide some of these in the table that follows.¹⁵ More resources are available at <https://myspectrumsuite.com>. The suggestions, sample responses and tips that follow were compiled from first-hand experience and anecdotal information in Craft’s communication with Autistic adults worldwide, and multiple resources. Some of the sample responses below can also be used to recognize when other people want their boundaries respected. For some Autistic people, some of these tips may require direct instruction.

Tips and responses for setting boundaries	
Preparation	<p>Preparing for interactions is crucial to successful boundary-setting, as is being aware of your values and the key reasons for your boundaries.</p> <ul style="list-style-type: none"> • Respecting yourself is important. It is not selfish. • Setting limits is needed. Without it, personal strain and burnout can happen faster. • There is a potential for miscommunication, bitterness and resentment when you are quiet. • Setting healthy boundaries is not the same as creating conflict, but it can create conflict if the other party is dismissive or invalidating. • Take care of yourself first. It is a kind and healthy thing to do. If you do not, you can be easily exposed to burnout or possible danger. • It's okay to feel uncomfortable (you may feel anxious) setting boundaries. • Examine roadblocks to healthy boundaries. This can happen through a discussion with a professional or trusted person, or by reading related literature. • Examine feelings associated with setting boundaries. For example, "I am afraid of boundaries because I _____ (fear hurting another's feelings, fear rejection, fear confrontation, will feel guilty, am afraid of what others will think about me)."
Analyze and support	<p>Analyze situations and seek the necessary support.</p> <ul style="list-style-type: none"> • What emotion(s) is underneath the initial discomfort? (e.g., anger, sense of danger, feeling invaded, personal space violated). Some people may not be able to answer this question and that is okay. • Practise identifying emotions when someone has violated a boundary by making notes of when these situations happen, how you felt and how you reacted. • It's okay to feel slow in recognizing situations and when boundaries are crossed. Learning this might be new and it takes time. Don't shame yourself about it. • Work on increasing your awareness level when your boundaries are violated. • Check in with a trusted person or support group if you are uncertain if a boundary has been crossed.
Action	<p>Below are some things to keep in mind when you are ready to set boundaries.</p> <ul style="list-style-type: none"> • Respect yourself. • Remember, you have the choice to ignore someone and walk away. • You get to decide the boundaries you set for yourself—the who, what, where, and when of your life without explaining the why. Nobody is owed an explanation or justification for your feelings. • Be as direct as possible. • Don't assume others know or understand your limits. • If you are able to, state your limits clearly and precisely, with as few words as possible. • Don't provide more information than needed. • Don't engage in an extended conversation, unless it's with someone with whom you have an invested and important relationship that you wish to keep.

<p style="text-align: center;">Sample responses</p>	<p>Having “go to” responses to how to express setting a boundary can be helpful. Below are some sample responses to refer to, or to practise with, when needed. You don’t have to use everything on here—you can pick your favourite ones and use them, or you can create your own.</p> <ul style="list-style-type: none"> • “No.” • “Stop!” or “I’d like you to stop.” • “I’m done,” or “I need to go now.” • “No, thank you,” or “No. I am not okay with this,” or “I’m not comfortable with that.” • “Not cool. Don’t do that around me.” • “This is my boundary. This is how much I can take.” • “This is not what I want to do.” • “I’ve learned it works for me best when . . .” • “I noticed you keep asking _____. Why are you asking me that?” • “I disagree and no longer am going to talk about this.”
<p style="text-align: center;">Stay calm and repeat</p>	<p>When setting limits, try to stay calm. Below are some tips to keep in mind when setting limits or responding to others.</p> <ul style="list-style-type: none"> • You don’t have to do this, but if possible, look in the centre of the other person’s forehead in order to appear to be making eye contact. • If needed, write your boundary on a piece of paper and read it aloud. • You do not have to always justify, but there are times when justification is necessary and helpful. Either party may need to understand why you need something to able to accommodate it. • You can feel angry, but if you want to get your point across, perhaps you have to say it calmly first. • Do not apologize. • Set a limit and repeat. (e.g., “I would like you not to cook in the kitchen after 10:00 p.m. Please stop cooking in the kitchen after 10:00 p.m.”) • Avoid indirect words and phrases that take away from being direct, such as: “I was wondering if”; “Can you do me a favour?”; “No big deal, but . . .”
<p style="text-align: center;">Advocate (see the section on self-advocacy below)</p>	<p>Advocate for your limits to be respected, exercise self-care and take actions to ensure you are heard.</p> <ul style="list-style-type: none"> • Know what you will and will not tolerate. • Keep to your words and honour that your needs and boundaries may be different than those of others but are just as valid. • Avoid debates, negotiations, arguments, shaming and threats. • If repeating limits does not have the desired outcome, you do not have to stay or continue stating your case. You can leave, walk away, ask for help, tell someone, etc. • Set limits for the other person. (e.g., “I need time to think if I can be in this relationship”; “I need to speak to someone about this situation before I make a decision”; “I have had enough and am no longer tolerating your behaviour/ this conversation”; “I will get back to you”; “I cannot help you.”) • Never remain in a dangerous situation. Leave and seek help immediately. • Reassure yourself that you did the right thing by standing your ground and looking out for yourself.

3. Build social support and avoid isolation

Many Autistic people find connecting with other like-minded people, the broader Autistic community and others with shared interests very valuable in reducing a sense of isolation. Many Autistic people are wary of non-Autistic-led groups, due to the fear of being misunderstood, labelled or stigmatized. Some Autistic people may say that they feel like they can remove their ‘masks’ around other Autistic people—they may feel seen and understood. It is sometimes referred to as “Autistic oxygen”¹⁶ by some advisers.

“I’ve largely had to build my own support network. I’ve had some government supports on logistics and mental health levels, but limited in a number of ways. I’ve been able to find mental health support from personal connections. I’ve never needed a lot of services; social development has been helpful financially and logistically over the years. Plus, my connections have helped greatly, being a huge networker.”

“When I first got my diagnosis, there wasn’t any group for Autistic adults in my community. While I found this to be discouraging at first, I created my own little circle of support by first creating such a group locally that was social and recreational in nature. Then, I created a support group that is Autistic-led that meets monthly. These opportunities provided others like me a ‘soft place to land’ for the newly diagnosed. For the Autistic adults in my community, it allowed for a place to connect and validate our experiences and to foster Autistic pride.”

Social support can improve self-knowledge and help Autistic people feel more connected with those around them. Accessing this support can be difficult, especially if travelling is hard or if there are no suitable groups nearby. Some Autistic people may find support through online communities. Online interactions can be helpful but can also harmful. It can be a way to connect, but it is important to be safe and know when to disconnect.

Reading books, magazines or blogs by Autistic writers can also be very validating and a good starting point in building social networks. Connecting through video-conferencing can also boost social participation and connectedness with special interest groups, support groups, virtual learning opportunities or individual therapy.

The images below are things to be aware of when building or finding support. **Red flags** (see image below) are attributes or behaviours that people should be careful of. These are qualities to watch out for in relationships and support.



Green flags (see image below) are attributes or behaviours that people should have in relationships. These are the qualities to look for in relationships and support.



4. Become informed

Many people look for formal and informal opportunities to learn more about their diagnosis, mental health and well-being. They find it helpful to learn as much as they can about their situation and how to deal with their challenges, including the causes, signs and ways of helping. The kind of information provided can affect mental health. It is important that Autistic people read explanations about autism that provide accurate and positive information. Negative stereotypes of autism that focus on pathology can foster internalized ableism, which in turn can affect mental health. **The List of Resources at the end of this guide provides a starting point for some self-directed learning for Autistic people, their families and advocates.**

“Using my research skills to become informed in my personal life has helped in moments when I’ve felt more introverted than ever. For example, toward the end of last year I was becoming more withdrawn when I was receiving praise at work from my boss saying I was awesome, because as well as keeping up with getting ready for Christmas (e.g., multiple work Christmas parties, gift making), I was not used to receiving that kind of praise from my supervisor, which did not necessarily include nods specifically to my work skills/projects. So, after initially trying to find out why I was feeling this way, I also looked online over the Christmas holidays for concrete tips on how to nicely receive genuine praise. Now I know that the baseline of simply smiling and saying ‘Thank you, _____’ is a great strategy to use whether or not I’m feeling worthy of that praise in the moment, as it reduces any potential awkwardness for the person who’s giving me the praise and I am graciously receiving it. It’s a win-win for both sides.”

5. Practise Autistic pride

Pride is described as a feeling of being worthy or having pleasure in what a person does or accomplishes. It involves a sense of happiness or confidence about one’s own qualities and characteristics. **Autistic pride** involves an Autistic person feeling proud to be Autistic and celebrating their differences and how Autistic people communicate, experience and understand the world around them (also known as **Autistic culture**¹⁷). It involves having a positive attitude about autism and celebrating these differences.

Every Autistic person is different. However, developing a strong sense of Autistic self-identity and creating a connection with other Autistic friends or acquaintances can be energizing and can lead to hopefulness and belonging. Understanding a person's identity and belonging plays a big role in well-being and self-care.

The idea of practising Autistic pride is expressed through a poem by the late Laura Hershey, a disabled poet, journalist and activist. The poem is called "You Get Proud by Practising" (www.cripcommentary.com/poetry.html#PROUD).

Autistic pride involves an Autistic person feeling proud to be Autistic and celebrating their differences.

Autistic culture is a "shared history, the way autistic people communicate, create, experience and understand the world around us in uniquely Autistic ways."¹⁷

"I think pride is something that one practises, not just experiences. Pride wasn't given to me from the sky. I had to work on it like a skill. If I don't practise it regularly, it is hard to stay proud. Especially when the whole world is constantly gearing up to tell me I am not worthy of pride."

6. Build a self-care plan

Self-care can lead to having more physical and emotional energy to deal with challenges, which can help people in the long term (see Activity 6.9). Being able to soothe, relax and calm oneself involves:

1. knowing what kinds of thoughts and behaviours make you feel better and
2. coming up with a self-care plan that helps you prevent or overcome negative feelings.

Developing a self-care plan can help a person to think about the small steps they can take in their life to have well-being. Imagine what a self-care plan might look like. This plan should address a person's needs in these areas:

- psychological
- emotional
- physical
- social
- spiritual.

The activity on the next page is called the **Biopsychosocial-Spiritual Self-Care Plan**. It can be filled out anytime and used during times of distress or when in good spirits. The point is to be very specific and realistic in the plan, so it can be achieved.

Activity 6.9 – Biopsychosocial-Spiritual Self-Care Plan

Fill out the boxes below with things you can do to exercise self-care. **Remember SMART goals: specific, measurable, achievable, realistic and timely.** It can be hard to set goals, and sometimes we set them too high for ourselves and that is okay. Then we just need to adjust. Below are just some examples of goals you can set:

- “I will go for a walk for 10–20 minutes two times a week.” (Physical)
- “I will go to _____ support group (with or without a friend) once every week.” (Social)
- “I will eat two fruits a day and take a B6 multivitamin.” (Biological)
- “I will message one friend a week.” (Social)
- “I will hug my pet three times a week.” (Emotional)
- “I will say ‘I am doing my best’ to myself if I get stuck on a task.” (Psychological)
- “I will meditate once a week.” (Spiritual)
- “I will write down something I’m grateful for two times a week.” (Spiritual)

Self-Care Plan	
Biological or Physical self-care	Psychological/Emotional self-care
Social self-care	Spiritual self-care

Information sharing, finding supports and self-advocacy

Information sharing

Being able to positively share information about being Autistic with others can be an important component of well-being. Choosing who to share information with and who to seek support from is a personal choice.

Before deciding on who to tell about a diagnosis, it may be helpful to ask the following questions:

1. Who do I feel I should tell?
2. Is this person ready for the discussion?
3. Is this person up for discussing the issues and concerns I have?
4. Is this person consenting for me to talk to them about the issues I'm having?
5. What am I looking for after I disclose?
6. How will I start the discussion? (By email, text, phone, videoconferencing or in person?)
7. What are the potential benefits to me and to the other person?
8. What are the potential risks or negative consequences of my disclosure? (Perhaps this one can be done with a trusted person who will help in recognizing what the potential risks are.)

This decision can differ from person to person. You may want to share information with someone you are close to, but at times, they may not be the right person to talk with. Sometimes the best person to talk to may be someone who is not as close to you or to the situation.

“If you ask someone if they have the time and energy so you can talk to them about ____ and they say yes, chances are they're a decent person to talk to.”

On the next page are some signs to keep in mind to recognize the right person to share information with.

Good Signs	Bad Signs
<ul style="list-style-type: none"> • They make you feel safe and comfortable. • They ask for sources of education or information on autism because they want to learn more about it. • They ask you what you need and how they can support or accommodate that. • They apologize for how they treated you, if they treated you negatively in the past. 	<ul style="list-style-type: none"> • They do not make you feel safe or comfortable. • They say they know what autism is and that they don't need any education on it. • They refuse to learn more about it when you offer. • They refer to autism as a "mental illness." • They say they don't believe you. • They say: "You don't look Autistic" or "You don't seem Autistic."

Even if other people may need to know about a diagnosis, it is important that the Autistic person be able to choose when and how to disclose this information.

Autistic experiences with disclosure

"I used to be wary about disclosing that I'm Autistic. Not so much anymore. I hide it from my family and some others. But, generally, if it's entirely up to me whether or not to have some kind of relationship with someone, then I won't hide it. A large part of the reason for this is that I haven't found it makes a difference in how I'm treated. The ableism I deal with comes from my communication style being a bit 'off' (i.e., different).

"Most people treat me differently than they treat non-Autistics right from the moment they meet me. And the reason saying that I'm Autistic seems to have no effect (good or bad) comes from an issue that anyone with an 'invisible' disability has to deal with: getting people to actually believe them. When I tell someone I'm Autistic, they'll often believe me in the sense that they'll consciously accept that I'm Autistic. But suppose I go into specific detail about what that means by, for example, explaining how my social behaviour is different and how accepting that usually requires they change their behaviour toward me (i.e., to stop trying to understand me by using their non-Autistic social rule book). Then they usually won't believe me and won't make necessary changes to avoid ableist behaviour. They'll tell me that I 'seem normal' or 'don't look Autistic,' demonstrating that, in a strong sense, they don't really accept that I'm Autistic even if they consciously think that they do."

“I have always felt proud of my autism since high school and don't have a problem disclosing it. But before that, I was more shy. I didn't disclose it, it was just something I never really thought about.”

Finding supports

There can be many resources that supply information about local support groups, agencies, clinics or hospitals. It can be hard for Autistic adults to figure out how to access and navigate these resources, if they even do exist—knowing which kind of support is useful and being able to obtain it.

In many parts of the country, there may be little to no supports for Autistic adults. The **List of Resources** at the end of this guide supplies examples of online, local, provincial and national resources as a starting point. Knowing what exists can empower a person to seek support—but **that support should be a good fit for the person.**

Autistic experiences with information-sharing

“I recently applied for a post-secondary program and thought I would, for the first time, register for student services. I thought I would be treated with dignity and respect, but instead it was a nightmare of them wanting family history and many other details that were not relevant to my diagnosis and needs as a student. Knowing what you really are looking for when sharing a diagnosis is important to preparing [for the] possibility of not getting it.”

“Support groups online such as Autistics 4 Autistics and regional Autistic groups can be a big help for Autistic persons with direct problems, as provincial support is limited after the age of 21.”

Self-advocacy

You can think of two kinds of self-advocacy: personal and collective. **Personal self-advocacy** is the process of getting a person's wants and needs met.

This involves letting others know what a person's own needs and wants are. **Collective self-advocacy** is advocating on behalf of one's self and others to improve the conditions and circumstances of a whole group of people. Autistic people should be empowered to take part in all aspects of life, and they have a right to access supports that meet their needs.¹⁸

Personal self-advocacy is the process of getting a person's wants and needs met.

Collective self-advocacy is advocating on behalf of oneself and others like them.

Every adult has the right to choose what to speak out about, what changes they want to make in their lives and what they need to do to bring these changes about. Advocates should have awareness, respect the rights of other people, and consider issues of health and safety. Self-advocacy is not an easy task for some advocates. Some Autistic adults are able to advocate for themselves with or without a partner to help them. Many have had to learn on their own.

If an Autistic person doesn't know where to start with self-advocacy, Kassiane Sibley, an Autistic self-advocate, developed a six-stage plan for successful self-advocacy for Autistic adults. The plan can be found in a chapter called "Help Me Help Myself" in Stephen Shore's book *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum*.¹⁹ Part of this plan involves connecting with a partner (a friend, mentor or family member) who is experienced at advocacy or advocating for them.

Advocating when overwhelmed

There are circumstances that cause great stress and can leave a person unable to communicate or organize their thoughts clearly, even if they are usually able to do so. In these situations, it can be helpful to have important information written down. For example, cue cards or phone apps could have phrases like "Don't touch" or "I am Autistic" along with a brief explanation. Contact information can also be placed on cue cards for use in case of emergency.

Autistic rights

Autistic people may grow up with a high degree of oversight and perhaps with caregivers, teachers and professionals telling them what they should be doing. As a result, Autistic people may benefit from being taught that they have intrinsic rights.

Learning how to have these rights respected and upheld is an important life skill and can help boost well-being.

It is important to know that every person has a right to:

- their own body
- their own identity (race, gender, sexuality, culture, etc.)
- their personal space
- respect and validation
- support from health care professionals
- ask for a second opinion
- education about autism and mental health
- information about the latest research and most effective supports or services
- speak to legal representatives.

Autistic experiences with self-advocacy

“My being a self-advocate for myself has been a learning curve. I am very familiar with articulating for myself when it comes to a presentation (e.g., my Autism on the Hill speech in April 2017). However, being a self-advocate for myself at work is much newer to me, and I am learning as I go. I am immensely grateful and lucky that all of my jobs are ones where the people (boss and colleagues) are familiar with disability issues and are proponents for inclusion and meaningful contributions.”

“I started giving talks about autism and being an advocate when I was 18 (18 years ago). When you get up in front of that crowd, your voice is like a sword in your soul. You need to be sure of what you want to say, what your point is and what parts of your truth can be used to get that point across.

“I like to use humour in my talks because I know if I made them laugh, I have their attention—and some of what I have to say will be heavy and hard to hear, so (depending on the talk) I want them to be able to laugh and remember feeling good where I can. And to see that Autistic people, and autism in general, is not all doom and gloom. But above all, your words are like a sword in your soul. You draw your sword only when you’re sure of your strike—because if you aren’t sure, you could wind up cutting something you didn’t mean to.”

“My autism advocacy started in 2007 with Autism Ambassadors and then Inclusion Ambassadors. I have been involved in numerous government and social support groups. NBACL [New Brunswick Association for Community Living] is another. Connect is one of the latest groups to be involved in. Some groups are better suited to Autistics than others. The ones I’ve mentioned have been awesome.”

“Becoming an advocate for my children helped me deal with my own childhood traumas related to growing up Autistic, being misdiagnosed and misunderstood. I knew how to think like my children, and I understood their social difficulties from the inside. Being able to strongly support my children and work for fair and equitable supports and interventions provided me with the beginnings of ASD pride. I wasn’t failing my children the way my parents/teachers/doctors failed me.”

“I have a trans friend who suspected he was Autistic. I attended many appointments with various service providers with him, to advocate and support him as he worked his way through assessment and diagnosis. There were times where having me along really helped the process move, because I was able to reframe the diagnostician's bias, so that my friend was not sent away without answers. Eventually, he was diagnosed by a clinician who was well-versed in assessing people who are not cis male.”

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