

Navigating the Healthcare System:

A Toolkit for Autistic Adults



Financial support
from AIDE Canada



Sinneave
FAMILY FOUNDATION

Powered by The Sinneave
Family Foundation (2024)

Table of Contents

Introduction	3
What Health Means to Me	4
How to Navigate Healthcare	5
Overview of Navigating Healthcare	5
The Patient's Medical Home	7
Finding a Doctor	8
What is Important to You in a Doctor?	9
Working With Your Doctor	13
When You Need Urgent/Emergency Help	24
Self-Advocacy	28
Finances	30
Final Thoughts	34
Appendix	35
Appendix A – How to Find a Family Doctor by Province and Territory	35
Appendix B – Supports for Seniors by Province and Territory	36
Appendix C – Resources for Your Doctor	37
Appendix D – Body Map	41
Appendix E – Pain Scale	42
Appendix F – Example of a Laboratory Requisition	43

Introduction

Welcome to the **Navigating the Healthcare System: A Toolkit for Autistic Adults!** This Toolkit was developed following the Impossible Conference hosted in 2023 by AIDE Canada. At the conference, Autistic adults identified that information and assistance navigating the healthcare system were areas of need.

Purpose:

This Toolkit guides Autistic adults and their support networks to navigate the healthcare system in Canada. The services and models of care described in this toolkit are based on what is current in Alberta; however, the content was designed to serve as a resource to those living in other Canadian provinces and territories. At the end of this kit, a doctor-specific section can be found that may help doctors and other health professionals increase their awareness of Autistic health needs.

Limitations of the Toolkit:

This Toolkit is a starting point and because of the diversity of autism and the wide variability of health needs at different ages, is not intended to address the needs of everyone. The Toolkit also does not address specific medical issues. It is important to note that health services vary across provinces and territories and each province and territory has a different way of offering health services to those living in that province or territory. Please check your own province's healthcare website for province specific programs.

Icons Used in the Toolkit:



Canada- wide
Canada-wide resources
available to all



Note

A short note about a unique
idea that might help you



Tips

Tips and ideas



Reflection Question

A question you can ask yourself

What Health Means to Me

Health means something different for everyone and while it often includes physical, mental, and social well-being, defining health is unique to each person.



Reflection Question: What does health mean to you?

Below are some examples of what Autistic adults told us...

“Health is when you are able to do the things that matter to you without excessive pain.”

“Health means happiness.”

“Health is doing whatever you want to do...going wherever you want to go.”

“A wholistic well-being. Body, mind, heart, spirit. And the means to fulfillment and enjoyment of life.”

“Health means enjoying a day. Having a body I can move and understand. Health is what contributes to quality of life.”

“Health means being able to get care when needed without excessive wait.”

Health means physical and mental wellbeing. Good health means getting support from the community.

Health is being active. Having my ability to react to most situations.

Security that my physical and mental health will be taken care of. Health is body and mind without pain.

How to Navigate Healthcare

Overview of Navigating Healthcare

For some people getting the healthcare they need is not difficult, while others experience frustration for a variety of reasons. If you have frustrating experiences, you are not alone. Navigating healthcare can have challenges which may create fear and anxiety for some people. These challenges can be overwhelming and that is why this toolkit exists.

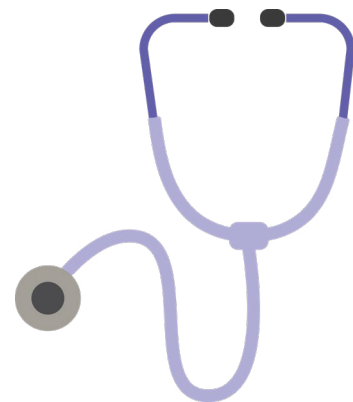
What are some reasons for these challenges?

Some healthcare professionals you encounter may:

- Have limited experience or understanding of working with Autistic patients, including being responsive to sensory and communication needs.
- Lack awareness and sensitivity to questions and concerns about sexual and gender diversity.
- Do not have training in the autism and the neurodivergence space.
- Have long waitlists (especially for specialists).

Other reasons healthcare barriers exist:

- A lack of family doctors in Canada.
- Limited research on Autistic health and healthcare needs.
- A complex and fragmented healthcare system.
- Expectations that aging parents support their Autistic adults even if their own health is failing.



Healthcare is Multi-Dimensional



Reflection Question: Who is part of your healthcare team?

The Patient's Medical Home

The first and most important step to navigating health care in Canada is to find a family doctor if you don't already have one. There are important benefits to you to have a family doctor who follows you throughout your life.

Your family doctor (also called your primary care physician) can offer an in-depth understanding of your health challenges and build a trusting relationship over time, which has been shown to improve your health.

As you age your health care needs will naturally change and may increase because of age-related health challenges. Having a family doctor becomes even more important as you age. Your family doctor is responsible for managing and coordinating your healthcare needs, also called continuity of care.

Your family doctor is your medical home. The idea of the [Patient's Medical Home \(PMH\)](#) is a place where you feel comfortable getting your health needs met. The medical home idea is the future of family medicine in Canada and has proven to give the best health outcomes.

In Alberta your doctor may belong to a Primary Care Network (PCN), which supports the medical home model. The Primary Care Networks offer family doctors easier access to more health services for you at no extra cost.

These services may include education classes, individual and group sessions for nutrition, mental health, and exercise. Some PCNs also offer extra services like a primary care nurse that can provide care and education for chronic conditions like diabetes or high blood pressure.

These professionals will report your progress back to your family doctor, so they are able to follow your progress and recommendations for further treatment. The benefit of this is that your family doctor is kept informed on any changes in your health to ensure continuity of care.



Coordinated Care

Patient's medical home:

- is the **centre** of patient/family care
- **aligns care** between specialists, hospital, community services, and others

Source: Alberta Medical Association Website

Finding a Doctor

If you do not have a family doctor there are ways you can find one. In Alberta, you can find out if a family doctor is accepting new patients and which PCN they belong to by going to www.albertafindadoctor.ca. Put in your address and it will show you which family doctors in your area are accepting new patients.



See Appendix A,
How to Find a Doctor by Province or Territory

You can also:

1. Ask your friends and family if their doctor is accepting new patients. Sometimes family doctors will take on new patients who are family members or friends of a current patient.
2. Call 811 which puts you in contact with a nurse in case of a non-urgent health issue. The service is available 24 hours a day, 7 days a week in any province or territory. You can get medical advice when you have questions.



There may be other options in your province if you cannot find a doctor. First, call 811 to find out other options. Your area may also have urgent care centers, walk-in clinics and pharmacists who can prescribe for minor illnesses. Pharmacists can manage some chronic conditions like asthma, diabetes, and high blood pressure. Talk to your pharmacist to see if they can help you.

3. Call 211 which connects you with a person who can tell you about local community resources in your area, like housing, health, employment assistance, and crisis intervention. This line is also available 24 hours a day, 7 days a week (in more than 150 languages). Call this number or go to the 211 website in your province to search for services. Chat or text for advice when you need help but are not sure where to turn. This service is available in all provinces and territories.

4. Talk to your pediatrician if you have one. Not everyone has a pediatrician (a doctor who specializes in children's health). Some children and young adults have a family doctor. If you do have a pediatrician, they may be able to recommend a family doctor for you when you turn 18 and the pediatrician cannot longer provide care.

In many provinces age 18 is when child funded programs end and adult services begin. This is a significant time of transition for many.

In Alberta, "Well on Your Way" is a program under Alberta Health Services with many free resources for transitioning into adulthood. Go to the Alberta Health Services [website](#) and search Well on Your Way. Not all provinces will have transition support programs; you may need to search for these where you live.



What is Important to You in a Doctor?

If you cannot find a family doctor you can use walk-in clinics and urgent care centres. This is not the best way to get life-long care because the in-depth understanding of your needs and coordination around your health is not possible in these settings.

At the time this document was written there was a shortage of family doctors in Canada, especially in rural and remote locations. Many doctors do not have autism-specific training, although some will be more familiar with autism. Look for a doctor who is open to listening to your challenges, communication style, sensory accommodation needs, and additional supports.





Consider what is **most** important to you when looking for a family doctor.

- **Empathy**

Do you feel like you are being heard and that the doctor is listening to you during the limited time of your appointment?

High Importance | Less Importance | Low Importance

- **Communication**

Can you understand the family doctor? Do they use language that makes sense to you and avoid speaking in confusing medical language? Your doctor should be able to answer your questions thoroughly so that you can understand and make informed decisions about your healthcare.

High Importance | Less Importance | Low Importance

- **Availability**

What hours does your doctor work? Is the clinic only open during the weekdays or do they have some coverage during evenings and weekends? How far in advance do you have to book appointments and if your need is time-sensitive, how do they manage that? Some PCNs in Alberta have access to after-hours clinics you can use.

High Importance | Less Importance | Low Importance

- **Physician Gender**

Do you have a gender preference for your doctor? The availability of both female and male doctors will vary depending on the area you live in. If you prefer a female doctor, some PMHs/PCNs may offer a nurse to provide women's health testing like pap smears and breast exams.

High Importance

| Less Importance

| Low Importance

- **Clinic Location**

How will you get to the doctor's office? Do you have accessible transportation to get there, or do you need a doctor who is closer to where you live?

High Importance

| Less Importance

| Low Importance

Disclosing your Needs

It is important to share specific details about your health needs with your doctor. Do you have specific health challenges, like diabetes, high blood pressure, mental health challenges or health concerns that may be difficult to talk about?

Conversations with your doctor are confidential. You have the choice to share whether you are Autistic.





Not all doctors have equal experience in providing care for Autistic patients, and discussing your unique needs can open important conversations and help ensure you receive the best care tailored to your needs. While disclosing this information may enhance your doctor's understanding of your needs and improve the quality of care, this decision is entirely yours to make.

In some cases, a doctor may be required by law to break confidentiality. These situations typically are if your doctor believes you are a harm to yourself or to others. If you want to learn more about confidentiality, check provincial laws that govern confidentiality. These laws can be found under the health information act for each province.



“When I first found a family doctor, she did not understand my needs as an Autistic adult. She was open and patient, and we talked about who I am. Now she does understand who I am, and what I need. It took a while and I was unsure, but it has worked out well.”

- Autistic self-advocate



Reflection Question: What qualities are most important for you for your doctor to have?



Working With Your Doctor

Now you have a doctor, knowing what to expect when you go to the doctor and helping your doctor understand who you are will help you get your best care.

What to expect when you go

Family doctors usually have 15-20 minutes per appointment and prefer that you ask about one medical issue per appointment. Some doctors are more flexible, and let you ask about a few health problems.

General guidelines for doctors are to offer a full physical exam (ages 22-64) once every 1-3 years. Over age 65, once a year for a full physical. Check with your doctor on what their guidelines are.

You can book appointments throughout the year when you have health concerns. Health concerns include mental health and not just physical health. If you are struggling with mental health, like depression, anxiety, or other experiences, your family doctor can help. They can prescribe medications and when appropriate refer you to a psychiatrist. If you are experiencing mental health issues, consider booking an appointment with your doctor. Sometimes, when you mention you want to discuss mental health, they will give you a longer appointment.



If you can't wait for the appointment and need to talk to someone immediately about mental health. **Dial 988, the Canada-wide suicide prevention number.** You can also **dial 811 the 24 hour phone-in service to talk to a nurse and to learn about local mental health and addiction services.** 211 has a [website](#) with topics like addiction supports and crisis resources where you can search your word and find services in your area. There is also a chat and texting option.




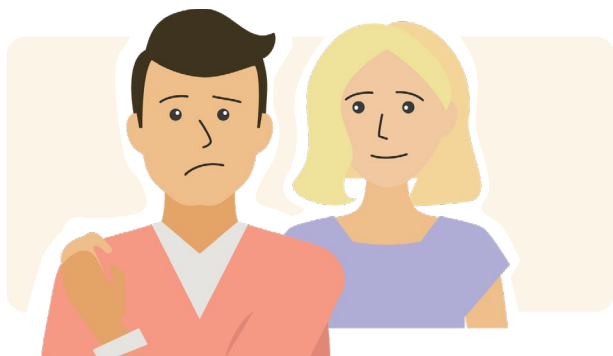
The [Autism Mental Health Literacy Project, York University](#) is an excellent resource for mental health.

Booking an appointment

When you need to see your doctor, you can call the clinic and ask to book an appointment. Tell them your name and the reason you need to see the doctor. Making an appointment is usually done over the phone. You may need to give details to the person on the phone who is part of the health team. Before you call to book the appointment, have your schedule with you and your support person's schedule, if you have a support person.

If it is your first appointment at the clinic and you have any accessibility needs, you can remind them when you call. Some clinics have an on-line booking option.

Do you need a support person?



Some Autistic adults prefer to advocate and manage their own health while others want to bring someone they trust to support them. You can choose to bring someone with you if you want. Managing your own health looks different for everyone.



Reflection Question: Would you benefit from having someone at your appointment to support you?

Consider These Questions:

1. I need help with:

- | | | |
|---|-----|----|
| Booking an appointment | Yes | No |
| Transportation | Yes | No |
| Understanding my health conditions | Yes | No |
| Navigating referrals | Yes | No |
| Remembering what I wanted to discuss with my doctor | Yes | No |
| Remembering what my doctor says in my appointment | Yes | No |
| Remembering to take medications yes/no | Yes | No |
| Other needs: | | |

1. I could get help from:

- | | | |
|--|-----|----|
| My parents | Yes | No |
| My caregiver(s) | Yes | No |
| My sibling(s) | Yes | No |
| My close relative(s) (aunt/uncle) | Yes | No |
| My group home staff, day program staff | Yes | No |
| My friend(s) | Yes | No |
| My social worker | Yes | No |
| My legal guardian | Yes | No |
| Technology | Yes | No |

Could Technology Help?

Technology options are extensive and always evolving. Some Autistic adults will not want to use technology, others are fully autonomous with the use of some technology. Healthcare technology does support some Autistic adults with their health and well-being.

Apps can allow you track symptoms, medications, and appointments, making it easier to manage your healthcare. Tracking these things can help you remember what to talk about with your doctors and explain how you feel.



While we mention a selection of apps here, we do not endorse or promote any specific ones. If you have questions about the apps mentioned here or others, we recommend contacting the app developers or go directly to the website for information.

Here are only a few examples of apps:



My Health Alberta: MyHealth Records lets Albertans view their health records, including immunizations, medications, and lab results, and share medical information. Available for free on the App Store and Google Play.



Bearable: The Bearable App lets people track their physical and mental health. It is customizable and can help individuals feel more prepared for their next doctor's appointment by compiling information. Available for free with optional in-app purchases on the App Store and Google Play.



Flo: Flo lets individuals track their menstrual cycle, fertility, and general reproductive health. It offers reminders and educational resources. Available for free with optional in-app purchases on the App Store and Google Play.



Canadian Migraine Tracker: This app lets people log migraine attacks, triggers, symptoms, and treatments. It helps make communication with providers easier. The app focuses on the information doctors usually ask for and offers reports to share with your provider in a PDF or an email. Available for free on the App Store and Google Play.

Finding Healthcare Apps on Your Own:

You can find more apps by searching keywords, such as 'health tracking' or 'symptom management' in the App store. You can also check online resources and forums where users share recommendations and reviews. Remember to read app descriptions, user reviews, and privacy policies carefully before downloading to make sure the app is right for you.

Your First Appointment – Communicating Your Needs

Some people have specific communication, sensory, body awareness, processing, organizational and/or planning needs. Communicating your needs to your doctor and the clinic staff may help them better understand you and provide better care.



Reflection Question: Is there anything your doctor and the staff need to know about your needs?



Thinking About What I Need

Communication:

Some people process words, facial features, and body language differently and may benefit from additional time to process information and want additional clarity to support understanding.

Do you have specific communication preferences?

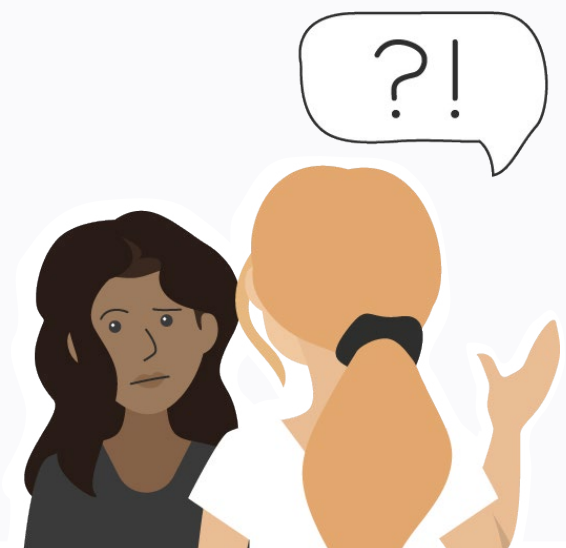
(e.g. You like to have information written down)

If so, what do you want the doctors, nurses and staff to know so they can give you better care?

(e.g., when possible, give me some additional time to respond to your question and describe the treatment plan in writing)

Social Interaction:

Navigating social interactions is challenging sometimes. People often expect others to follow various social rules. There are many social rules that exist, not all rules apply in all situations. This can be confusing.



Do you socialize differently?

(e.g. I prefer to look away from the speaker or over their shoulder and not directly at their eyes).

If so, what do the doctor/nurse/staff need to know to give better care?

(e.g. don't assume if I'm not looking you in the eye that I am rude or that I am not hearing or understanding what you are saying)

Sensory Experiences:

Everyone experiences senses differently. Some sensory experiences can be exhausting, discomforting, or even painful. Suppose you are hyper-aware of a specific sense. In that case, you may want more or less of it, making certain environments challenging. Sensory areas can include sound, sight, smell, taste, touch, balance or understanding where your body is in the space around you.

Do you have specific sensory needs?

(e.g. I need dim lighting)

If so, what do the doctor/nurse/staff need to know to give better care?

(e.g. I can ask if they have dim lighting or light covers, but if not, I can wear sunglasses)



Communicating Your Needs

Here is an example of what you could say and/or show the doctor/nurse/clinic staff:

I'm Autistic, and doctor visits can be quite stressful for me. I'm hoping we can work together to create an environment where I feel supported and understood. I have prepared a list of accommodations to help me feel comfortable during my appointment. Would it be okay if I share this list with you, or is there a preferred way for me to communicate my needs effectively? Your understanding and support mean a lot to me. Thank you.

Put your **own** examples here that are specific to you.

Here are some examples of what has helped others...

- Please use clear, literal, and brief language when talking to me to make sure I understand.
- Ask me anything you need to know, as I may not always think to volunteer information.
- Provide clear instructions and check my understanding to ensure I follow your guidance accurately.
- Please offer me the option of a quiet space or room to wait in if the waiting area is noisy or overwhelming.

- I may be wearing noise-cancelling headphones in the waiting room, so please don't assume I'm not present if I don't respond to my name being called. Please approach me if I miss when you call my name.
- Give me extra time to process what I am hearing and to find the right words to respond. I might not answer immediately.
- Allow me to ask follow-up questions to clarify any uncertainties I may have.
- Understand that I have unique sensory needs. Please respect my boundaries regarding touch and provide advanced warning before physical contact.
- Allow me to express any fears or concerns I have about pain and understand that I may have heightened (or lowered) sensitivity to pain.
- Please explain procedures and tests as you are doing them, so I understand what is going on.
- I may respond very directly at times, but please understand that I am not trying to be rude. I may not always be aware of my tone.
- Sometimes my facial expressions may not accurately reflect how I'm feeling. Please do not assume I'm feeling a certain way based solely on my facial expressions.



Describing Pain

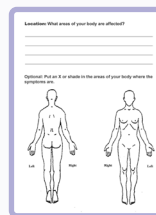
Some Autistic adults find they cannot explain pain or locate the source of pain as easily.

If you have pain, it may be helpful to think about how to describe your pain before you go to an appointment. This tips below are for your own reference. When you see your doctor do not tell them every answer on this sheet. This is intended to help you describe your pain in a few sentences when your doctor asks you.

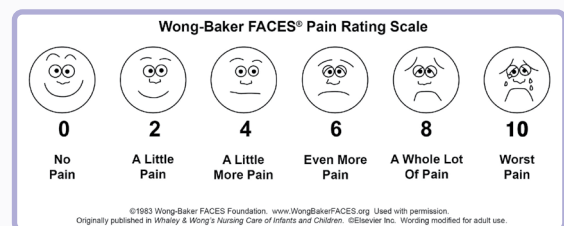


Thinking About How to Describe Pain

- If you can locate the area of your body where you feel pain, you can use this body map to show the doctor.
- How long has the pain been going on?
- Is there anything you find that makes it worse or better?
- Do other people around you have the same symptoms?
- How has the pain affected your life? Does it keep you from doing things that you normally do?
- Some people find it helpful to try to identify the level of pain by looking at a scale of little pain to high pain. Not all Autistic adults will find this useful especially if your facial expressions do not match how you feel.



Click the image to the left to jump to the enlarged, printable version located in **Appendix D**



Click the image above to jump to the enlarged version located in **Appendix E**

- **Note for caregivers of an adult who is non-speaking:** Some ways they may seek to communicate pain might include aggression, pacing, jumping, self-injury (not always at the source of the pain), sudden exaggerated movements, crying, and/or withdrawing.

Leaving the Appointment

Click the image above to jump to the enlarged, version located in **Appendix F**

Do you have your questions answered? Do you have all requisitions you need? A requisition is a written request by your doctor on a special laboratory form for some tests like blood work and x-rays. Your doctor will give you the requisition at the end of your appointment and you are responsible for booking the appointments for these tests.

Specialist appointments are coordinated by the doctor's office. The doctor or the specialist will contact you with the appointment date and location. You may wait for long periods of time to see a specialist. You can call the specialist office to ask to be put on a cancellation list which means an earlier appointment

may become available if others cancel. Phoning your family doctor will not help. Your doctor may give a timeframe when you leave the appointment of how long you might have to wait to see the specialist (e.g. 4-6 months, one year or longer).

Medication Management is important. Does your doctor update your medications and inform the pharmacy, or do you tell the pharmacy? Know when your medications are running low and when you need to reorder. You may be taking several medications at the same time, and as you age the number of medications may increase depending on your health needs. Some people use medication Apps, phone reminders, pill boxes, and/or notes on a bathroom mirror as reminders to take their medication.

You can also ask the pharmacist to make a 'blister pack' for you of your medications if you have many. A blister pack is a flat piece of cardboard displaying your medications in a clear plastic case with the exact medication you need to take each day of the week already organized for you. Talk to your pharmacist if you want to know more.

This is what a blister pack can look like:



When You Need Urgent/Emergency Help

When you have an urgent health issue and you do not have a family doctor, or your doctor cannot see you immediately, you may need to go to urgent care or to the emergency department.

Urgent Care vs Emergency Department Care. There is a difference between urgent care and emergency care. Urgent care centres are for illnesses or injuries that require same day, same evening treatment but are not life-threatening. The Emergency Department is for serious life-threatening issues that are considered a medical emergency.

Before You Go to Emergency....Ask yourself these questions.

1. Is this a life-threatening emergency? If yes, call **911** (an ambulance will arrive) or find support to go to the emergency department immediately.
1. If it is not life-threatening, you call contact your doctor's office for an appointment. Some doctors may be able to get you in the same day, You can also go to an urgent care centre.

If you are not sure, call 811 to talk to a nurse 24 hours a day, 7 days a week.



If you are feeling depressed or suicidal, there is a suicide prevention line for Canadians. Support is free and available 24 hours a day, 7 days a week; dial **988**.

You Have to Go to Urgent Care or The Emergency Department...



If you have to go to urgent care or the Emergency Department you may find these stressful places to be. Challenges you may encounter can be environmental noise, lights, smells, visual (people in pain, bleeding etc.), long wait times (4-8 hours or more), busy health care workers who do not know your history, long waits for tests and procedures that may be ordered to help you (e.g. x-rays, blood tests).



GOING TO THE EMERGENCY DEPARTMENT (urgent care will be similar)

If you go to the Emergency Department and you are not in life threatening condition, you may wait a long time. Even if you are having trouble breathing or in pain you may still be asked to wait unless it is life threatening.

What do you need to bring?

- Two pieces of identification, one with a photograph, one that has your legal name and date of birth, and your Health Care Information Card.
- Items that help you to stay calm if you need these (e.g. music, iPad, headphones, social story). It is recommended not to bring valuable items.

- A support person if you have one.
- Notes about what you are experiencing (for example pain).
- Notes about 'Communicating Your Needs'. Because of the busy nature of Emergency Departments the staff may not be able to accommodate certain requests, like quiet spaces or other needs.
- Snacks and water, but before you eat or drink, check with the triage nurse if that is OK. Depending on your injury they may request that you do not eat or drink.
- Cell phone and charger.

What to Expect When You Get There

When you walk into the Emergency Department you will see a waiting room, a triage station, a registration desk, and a security desk. You will be asked what you need and in most cases be directed to the triage nurse.

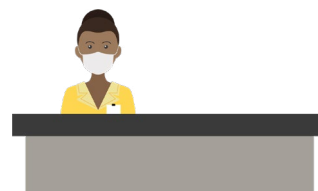
• Triage

The nurse will ask you your main concern. They will check your vital signs including heart rate, blood pressure, breathing rate, oxygen levels and temperature. After the nurse assesses you, they will send you back to the waiting room or take you into an exam room. You can ask the triage nurse at this time if you can eat or drink while you are waiting. If you have a concussion the nurse may ask that you not use headphones.



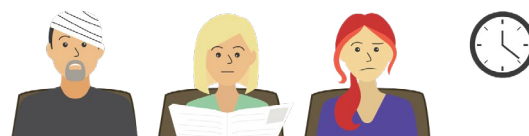
- **Registration**

You will usually be directed back to the waiting room to wait to be called by the registration clerk. When it is your turn, you will be asked for a second piece of identification, your healthcare card, name, address, phone number and emergency contact. You will be given a wrist band for identification. The band may feel uncomfortable, but it is important to leave it on when you are in the Emergency Department.



- **The Waiting Room**

You may be waiting a long time to see the doctor. It likely will not help to ask the registration clerk how long the wait will be. The Emergency Department staff see life-threatening cases first, even if they arrive long after you have been there.



- **Seeing the Doctor**

When your name is called you will be taken into an exam room. The doctor will ask you to explain what happened and may order tests and/or blood work. All of this is done in the Emergency Department or in other areas of the hospital. The doctor will decide what the treatment will be after they examine you and see the test results. You may go home with instructions, or be admitted to the hospital. Your family doctor will receive all the information about your visit.



The Emergency Department is a confidential environment, and you may consider disclosing that you are Autistic to help medical staff understand you better and give you better care. It is always your choice whether to disclose or not to disclose.

Self-Advocacy

“I need you to listen and hear what I am saying. Please do not brush it off if you don’t understand. I didn’t understand for many years either, but once I embraced it my whole world opened up. With some of your precious time, some understanding, and some grace I guarantee your world will open up too.”

- Autistic self-advocate

Self-advocacy is a tricky topic. Speaking up for yourself is difficult for many people. If you are not confident speaking up, you can start with some self-reflection.

You might ask yourself these questions:

- Do I speak up for myself?
- Am I able to do so?
- If I can’t speak up, is there someone who can help me?
- What do I say?
- How do I make myself heard and understood?
- Do I want to speak up for myself?
- Have my words been disregarded so many times I feel they are not worthy to be heard?

How do you learn to self-advocate? It is difficult for many to clearly express and advocate for themselves. When it comes to your medical needs, the extent to which you speak up and self-advocate may impact the quality and effectiveness of care you receive.

Here are a few ideas to consider if you are not confident in self-advocacy:

- Practice Speaking for Yourself: Speaking for yourself verbally or non-verbally through pictures or other communication forms, is important. It is important to speak for yourself (or use pictures) if you can. Practice the conversations with a family member, friend, or a support provider.
- Know What You Need: Taking time to understand your experiences and knowing what helps you will make it easier to communicate those needs.
- Tell Others: Use the 'Communicating Your Needs' tips in this kit to help other people understand you.
- Bring a Support Person. Bring someone with you who can represent you and advocate for you.
- AIDE Canda has a toolkit with ideas and resources on self-advocacy. On the [AIDE Canada website](#) search for the **Transition to Adulthood Services: Continuing to Foster Self-Determination, Choices, and Self-Advocacy** toolkit.

“If I know I need an extra “brain,” I bring someone who can function as an advocate for me. I was at the neurologist a couple of weeks ago, and I brought someone with me. I was told, after a discussion with the receptionist my companion could not come in with me for the first part of the appointment. So, I went in on my own...we did the first part of the exam and then the doctor left the room. I didn’t really understand what was going on and then he came back in. Not a word was said about my companion not coming in, so he carried on with giving me the diagnosis. I’m not sure I understood everything he said, and I forgot to ask him some questions (even though I had a list), which I know my companion would have asked.”

- Autistic self-advocate

Even self-advocates sometimes need extra help. Be clear if you require a companion to get all the information you need.



The Canada Health Act gives you guidelines on how the Canadian government is responsible to help all people of Canada maintain and improve their health. Each province has a patient advocate office. Check your own province for the provincial health advocate. Call **211** in your province to find the provincial advocate for health.


Finances

An important part of healthcare is getting the financial support you need to cover healthcare costs. As you age there may be changes in financial supports, but you can plan for these changes.

In Canada, most provinces and territories have access to healthcare for their residents under the Canada Health Act. Regardless of your age, you will have free family doctor visits, emergency room care, basic hospital care, and medication costs while in hospital. Some provinces/territories may charge a small fee for health coverage. In Alberta there is no charge.

Although in Canada many health care costs are covered, some health costs are not. Medications, dental costs, and physiotherapy are a few examples of costs that may not be covered in your province.

You may be eligible for an income support program when you turn 18. In Alberta this program is called Assured Income for the Severely Handicapped (AISH). <https://www.alberta.ca/aish>. If you are eligible, AISH provides a monthly income and also covers a variety of other health costs, like medications, dental costs, and special diets up until the age of 65.



If you are on income support programs, check the details of your program to see what is covered and be sure to get the most financial assistance you are eligible for.

“I support a young man who is now 25 years old. He recently moved into our group home. He is non-speaking. The first two years were difficult as he is a picky eater, and we (the staff) all cook differently. He started to lose weight. We went to see his family doctor and she suggested that he get a nutritional drink with extra calories and protein. She put in a request to the pharmacy, and the cost was covered by AISH. This small change alone helped him regain weight. We did not know that the income support program would pay for that.”

- Support Provider

If you need more health coverage, and do not qualify for an income support plan like AISH, you can pay privately for province-based programs like [Blue Cross](#) in Alberta. In Canada, each province and territory are responsible for private pay health care programs.

If you are working, many employers offer benefits that cover some health costs. In Alberta, the [Alberta Adult Health Benefit \(AAHB\)](#) are health benefits for low-income Albertans, not covered by work insurance plans. Each province and territory will have their own programs.

As You Age

As you get older it is important to understand details about age related changes that impact your health coverage. [The Canada Pension Plan \(CPP\)](#) is available when you turn 60 if you have worked and contributed to the plan. You can decide when you want to start to receive this support. CPP gives you a monthly income and the amount depends on how long you worked and contributed over your working years. CPP does not however pay health related costs, like medications or dental care. The monthly amount increases if you choose to delay and start at a later age.

To qualify for CPP you must:

- Be at least 60 years old
- Have made at least one valid contribution to the CPP (can be either from work you did in Canada or receiving credits from a former spouse at the end of the relationship)

If you are turning age 65

Turning 65. This age is a big deal for many reasons. Like age 18, the age of 65 is another significant transition in your life where programs and funding change. For example, your provincial income support program (like AISH) may end at 65. AISH covers additional health costs, like dental costs and medications. That is an important change in funding.

When you turn 65, other programs may be available to cover costs. You will need to search your province specifically to find out about these programs. See Appendix B.



For most government programs you will need to apply and meet the eligibility criteria. If you have a support provider, friend, or local agency that helps you, they may be able to assist you in filling out the forms.

In addition to CPP, there are other Canada wide programs you may be eligible for.

Guaranteed Income Supplement (GIS):

The GIS is a monthly payment you can get if you are 65 or older. It is based on income and is available to those with low income. GIS like CPP do not pay for health costs like medications and dental care.

Old Age Security (OAS):

OAS is a monthly payment you can get if you are 65 and older. Eligibility is determined by how long you have lived in Canada after the age 18.

The Canadian Dental Care Plan (CDCP):

In 2023, the Canadian government began this plan to help cover costs for dental care for eligible Canadian residents who fall into the income eligibility category and who do not have access to dental insurance. As the programs starts, the funding begins with older ages. Check the website to see when you may be eligible to apply.

Some Programs are Province Specific:

Alberta Blue Cross

- Alberta Blue Cross provides seniors with free coverage for some prescription medications and other health-related services. To ask questions about your health care plan contact the [Alberta Health care Insurance Plan \(AHCIP\)](#)

Alberta Seniors Benefit:

- This benefit is for seniors with low-income to get financial assistance to help with monthly living expenses.
- You must have lived in Alberta for at least 3 months immediately before applying and receive the Old Age Security pension from the Government of Canada. Read your provincial program seniors' coverage carefully to find the province specific coverage (see [Appendix B](#)). Each province is unique in what it offers. For example, some provinces offer funds to help you stay in your home longer by paying for home heating, cooking, meal prep, groceries, meal delivery, foot care, and mental health supports, all in your home.

Final Thoughts

We hope this toolkit helps you get the best healthcare possible. If you want to watch the video that goes with this kit, go to the [AIDE Canada website](#). from the drop-down menu (Resources), click on Articles, Courses and Videos, search Navigating Healthcare, then click the 'Go' button.



Reflection Question: What does health mean to you? What steps can you take to enhance your health and overall well-being?

Acknowledgments

Special thanks to lived experience advisor Terri Robson, Tanya Kendall Consulting, and Carolyn Dudley, Project Lead, The Sinneave Family Foundation.



APPENDIX A

How to Find a Family Doctor by Province and Territory.

811 can also help you

British Columbia: The B.C. College of Family Physicians recommends patients contacting HealthLink BC 811 where a health service navigator can help provide information on how to find a doctor in your area.

Saskatchewan: The College of Physicians and Surgeons of Saskatchewan also has a where to find a family doctor available for patients.

Manitoba: The provincial government has a tool called the Family Doctor Finder where patients can register online or by phone so they can be connected with a clinic in the area.

Ontario: Patients can register with Health Care Connect to be put on a waitlist to find a doctor. They can also use the doctor search tool on the College of Physicians and Surgeons of Ontario website.

Québec: The provincial government has a waitlist where patients can register. They can also register over the phone.

New Brunswick: The province has a registry called Patient Connect to match residents with a family doctor if they don't already have one.

Nova Scotia: The province recommends patients call 811 or register with the Need a Family Practice Registry, which is a waitlist.

Prince Edward Island: Residents can join the Provincial Patient Registry and a doctor will be assigned when one is available

Newfoundland and Labrador: Patients can search a list of family physicians in their area to find a family doctor that are taking new patients.

Yukon: The territory has a match service for patients needing a family doctor.

Northwest Territories: Patients can reach out the Health and Social Services Department for guidance depending where they live

Nunavut: The territory's Department of Health provides contact numbers and a map to health-care services where family physicians can be found.

APPENDIX B

Income Supports for Seniors by Province and Territories

211 can also help you

British Columbia

[Supports for Seniors](#)

Saskatchewan

[Seniors Income Plan \(SIP\)](#)

Manitoba

[55 Plus Program](#)

Ontario

[Ontario Guaranteed Annual Income System](#)

Quebec

[Seniors 60 and Older](#)

New Brunswick

[Seniors – Low-Income Seniors” Benefit](#)

Nova Scotia

[Nova Scotia Seniors Services:](#)

[Supports to Help Seniors Stay in Their Homes | Government of Nova Scotia News Releases](#)

Prince Edward Island

[Prince Edward Island Seniors](#)

Newfoundland/Labrador

[NL Income Supplement and the NL Seniors' Benefit](#)

Nunavut

[Senior Citizen Supplementary Benefit \(SCSB\) – Nunavut
nunavutseniorhandbook_eng.pdf](#)

Yukon

Supports for Seniors and Vulnerable Adults:

[Apply for a low-income senior's income supplement | Government of Yukon](#)

Northwest Territories

NWT Senior Citizen Supplementary Benefit

<https://www.gov.nt.ca/en/nwt-senior-citizen-supplementary-benefit>

APPENDIX C

Resources for Your Doctor

Although this toolkit is intended for Autistic adults, we wanted to include some resources for those health professionals who are interested.

General Resources

Six Principles Sinneave Family Foundation.

The Sinneave Family Foundation, in collaboration with a team of autistic self-advocates, developed Six Principles to inspire greater understanding and acceptance of the natural differences between people and provide easy to implement actions that enhance inclusion for everyone.

<https://sinneavefoundation.org/thriving-in-adulthood/six-principles/>

Autism General Resources, Autism Canada.

Autism Canada's resource page offers various support services, tools, and information tailored for Autistic individuals, caregivers, and professionals.

<https://autismcanada.org/resources/publication/>

Peer-Reviewed Resources on Autism in Canada, AIDE Canada.

The AIDE Canada resource hub is a valuable platform offering trusted and peer-reviewed sources tailored to Autistic and neurodivergent individuals.

https://aidecanada.ca/?gclid=Cj0KCQiAnfmsBhDfARIsAM7MKi2iP3w3rITHi4V8h2Xo0zG6Ceen1a_QppxZLbFa_dTNcITQ-XpmwJ4aAoaREALw_wcB

Autism Mental Health Literacy Project, York University.

The Mental Health Literacy Guide for Autism is an essential resource that explores Autistic mental health.

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

Disability and Sexuality Lab, Resources for Service Providers. The focus of this resource is to promote social change by co-creating research and resource with communities to tackle silences around disability and sexuality, this section of the website gives comprehensive tools, guides and materials designed to enhance knowledge and skills of service providers.

<https://www.disabilitysexualitylab.com/work/resources-for-service-providers>

AASPIRE Healthcare Toolkit.

This resource has worksheets for healthcare providers and patients and focuses on primary health care with a regular doctor. US based.

<https://autismandhealth.org/>

Physician Practice Resources

Health Care Access Research and Developmental Disabilities (HCARD).

This website / platform provides many toolkits and resources developed to assist health care practitioners, including a best Practice Series of videos that demonstrate common practice errors followed by strategies to improve medical encounters.

<https://www.camh.ca/en/professionals/professionals--projects/hcardd>

Caring for Patients on the Autism Spectrum.

This website aims to guide care for Autistic patients, offering many insights and tools for physicians. Their tool, Autism Healthcare Accommodations Tool, empowers patients to communicate how autism affects their healthcare needs and suggests strategies for quality care. Additionally, the site provides information about communication, interactions, sensory

needs, body awareness, pain, sensory processing, planning, organization, and navigating exams and procedures, ensuring comprehensive support for healthcare professionals. US Based.

https://autismandhealth.org/?a=pv&p=main&t=pv_fac&s=fac_fac&theme=ltlc&size=small

Autistic SPACE: A Novel Framework for Meeting the Needs of Autistic People in Healthcare Settings. Doherty, M., McCowan, S., Shaw, SCK. British Journal of Hospital Medicine, April 2023.

This article explains the SPACE framework, which helps doctors understand and meet the needs of Autistic individuals in healthcare settings. It covers five core needs; sensory, predictability, acceptance, communication and empathy.

https://www.magonlinelibrary.com/doi/full/10.12968/hmed.2023.0006?rfr_dat=crpub++0pubmed&url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org

ASD Clinical Practice Resources, Canadian Paediatric Society.

The Canadian Pediatric Society offers valuable guides for diagnosis and support to guide physicians with resources, like checklists for post-diagnostic steps.

<https://cps.ca/en/autism>

Raising Awareness about Autism: Some tips for clinicians, CAMH.

This resource offers tips for clinicians on navigating autism and mental health. Tailored suggestions aim to make mental health services more autism-friendly, providing healthcare professionals with practical strategies to support Autistic individuals. Whether you are a clinician seeking guidance or simply wanting to learn how to enhance autism-friendly practice, this resource offers valuable information for promoting inclusive mental healthcare.

<https://www.camh.ca/en/camh-news-and-stories/raising-awareness-about-autism-some-tips-for-clinicians>

Autism Resources for Medical Professionals, Autism Alert Inc.

This resource hub is for medical professionals working with Autistic individuals. It offers many peer-reviewed articles on patient management and working with Autistic patients alongside practical tools like the form, 'What you Should Know About Me'. This form allows patients to express their social and communication needs, enhancing patient-provider understanding and care experience. US based.

<https://www.autismalert.org/index.php?page=resources-for-medical-professionals>

What's An Autism-Competent Office? Harvard Medical School.

This resource is designed to help make office spaces autism-friendly, benefiting everyone. This guide offers practical steps to create inclusive environments, and they provide a clinician course focusing on designing autism-friendly spaces and training staff for better patient care. Additionally, they offer a tip sheet to empower patients to advocate for autism-friendly care while directing clinicians on how to provide it. This resource promotes accessible and including environments for all.

<https://adult-autism.health.harvard.edu/resources/what-does-an-autism-competent-office-look-like/>

Make your Practice Friendlier for Adults on the Autism Spectrum, Physicians Practice.

This resource can help physicians create a more welcoming environment for Autistic patients, offering practical tips and resources from simple adjustments to more comprehensive ideas.

<https://www.physicianspractice.com/view/make-your-practice-friendlier-adults-autism-spectrum>

Autism and Neurodiversity in Primary Care (ASD) - Recognize and Refer, UBC/CPD in partnership with CIRCA.

This free, self-paced course is tailored for Canadian healthcare professionals. The purpose of this online course is to support primary care providers to learn more about the unique needs of their autistic patients and learn about practical and useful strategies to adapt their practice to better serve this population.

<https://ubccpd.ca/learn/learning-activities/course?eventtemplate=177-autism-and-neurodiversity-in-primary-care-asd-recognize-and-refer>

Clinical Care for Autistic Adults, Harvard Medical School.

This on demand course is tailored for healthcare professionals working with Autistic patients or planning to do so. Designed to inform and inspire, it empowers physicians to deliver personalized care for individuals and their families. The course is available from July 31, 2023, to July 30, 2026.

<https://cmecatalog.hms.harvard.edu/clinical-care-for-autistic-adults>

Annual Autism Conference, Alberta Medical Association.

The Autism Conference is an annual event the Alberta Medical Association runs, held virtually and in person.

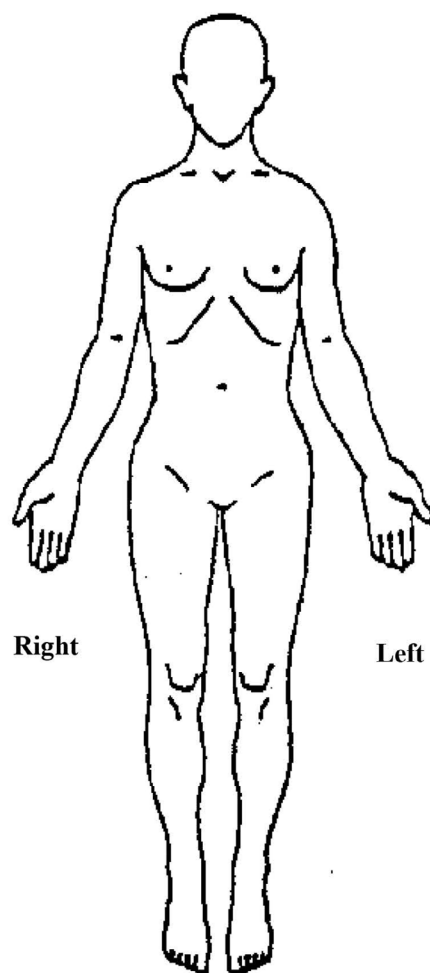
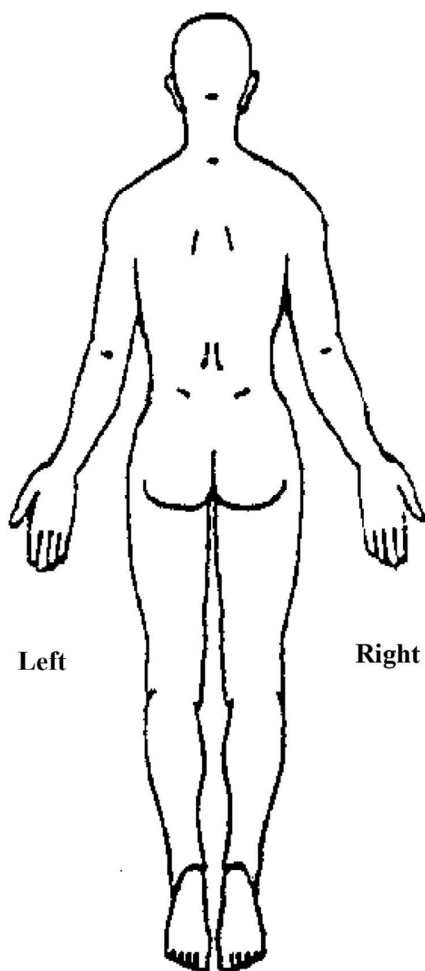
<https://www.albertadoctors.org/Events/annual-autism-conference>

APPENDIX D

Body Map

Location: What areas of your body are affected?

Optional: Put an X or shade in the areas of your body where the symptoms are.



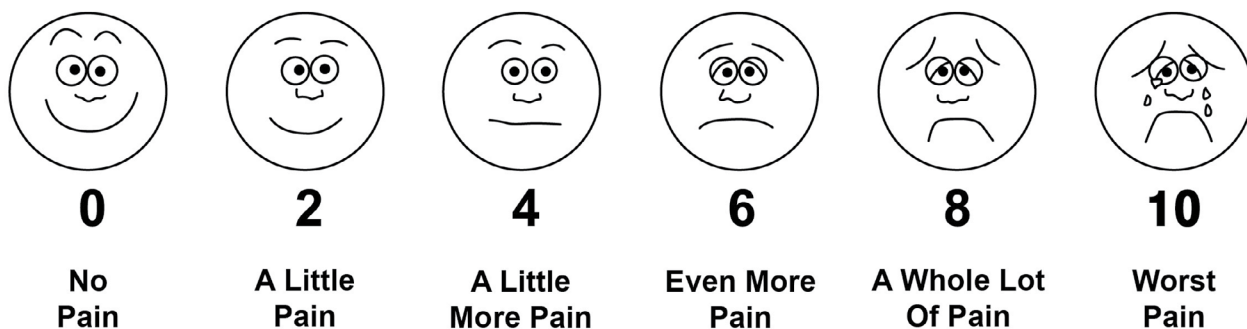
APPENDIX E

Pain Scale

The below Pain Rating Scale consists of six faces with each face representing a person who has no pain, or some, or a lot of pain.

This is a self-assessment tool that can aid in describing the pain you experience. If you do not understand the scale or are unable to indicate which face most closely depicts your pain experience, refer back to the **Thinking About How to Describe Pain** section of the **Navigating the Healthcare System - A toolkit for Autistic Adults** on page 22.

Wong-Baker FACES® Pain Rating Scale



©1983 Wong-Baker FACES Foundation. www.WongBakerFACES.org Used with permission. Originally published in *Whaley & Wong's Nursing Care of Infants and Children*. ©Elsevier Inc. Wording modified for adult use.

Face 0 - No pain.

Face 6 - Even more pain.

Face 2 - A little pain.

Face 8 - A whole lot of pain.

Face 4 - A little more pain.

Face 10 - Worst pain you can imagine, although you don't have to be crying to have the worst pain.

Choose the face that **best depicts** the pain you are experiencing and refer to the Wong-Baker FACES® Pain Rating Scale when speaking to your doctor.

Example of a Laboratory Requisition

21302/Rev(2024-01)