# Accessing Gender-Affirming Care as an Autistic Person

#### **About This Document**

This document is for autistic people who want gender-affirming care. Gender-affirming care is a type of health care for trans people, such as hormone medications and surgeries. This document was written by a trans autistic researcher. The researcher asked 12 trans autistic people about their experience of gender-affirming care in Ontario, Canada. This document has these people's ideas to help other trans autistic people. The researcher also asked trans autistic people to read the document and help make it better.

This document is not medical or legal advice. Most of the information could be used by any trans autistic person, but some resources are specific to Ontario. Not all of the advice will be helpful for everyone. Feel free to ignore anything that isn't helpful for you. The document is written in simple plain language to be accessible to people with different reading abilities. Click on <u>underlined text</u> to follow links to other websites. Or, visit <u>linktr.ee/transautisticresearch</u> or scan the QR code to access all of the links.

These shapes have quotes from trans autistic people that the researcher talked to. For privacy, the names are made-up.



## **Gender-Affirming Care in Ontario**

All family doctors in Ontario can prescribe hormones. Doctors with extra training can refer people for gender-affirming surgery. Some doctors don't know very much about gender-affirming care. These doctors might send you to a different doctor who has more experience.

A gender-affirming care clinic can help if you don't have a family doctor. Some community health centres have gender-affirming care programs. You can also ask a doctor at a walk-in clinic to refer you to the <u>Gender Identity Clinic at the Centre for Addiction and Mental Health (CAMH)</u>.

## **Accessing Health Care**

#### What to Expect

Doctors around the world follow instructions for gender-affirming care called the <u>WPATH Standards of Care</u>. In Ontario, most doctors also use <u>a guide from Rainbow Health Ontario</u>, also known as the Sherbourne guidelines.

Many doctors today use informed consent for gender-affirming care. This means that your doctor should tell you about the risks and benefits of a medication or surgery. They should help you decide what to do. But your health care is your choice. Rainbow Health Ontario says that a doctor cannot stop you from having gender-affirming care just because you are autistic. They say: "If you have the capacity to consent, you are allowed to make decisions for your body and your health, even if it is a decision that other adults may not agree with."

You should not have to prove or defend your gender identity. However, your doctor may need to diagnose you with gender dysphoria so that insurance will pay for your medication and surgery.

#### **Navigating the Healthcare System**

Gender-affirming care can involve many different people, places, and systems. If you find this confusing or hard, you are not alone!

Completing forms can be hard for everyone, especially for autistic people. You can ask someone for help with a form. This person can read the form aloud, write things down, or sit with you while you fill it out. You can also ask them to help make phone calls or send emails.

Your local community health centre may have people that can help you complete a form or find help. They might be called social workers, intake workers, community workers, or peer support workers. You can also ask your doctor for help with this. "I feel grateful for the help that was the internet. I got to pre-plan and understand all of the various things that would come along with these kinds of discussions."

-Ivan

## **Communicating With Doctors**

## **Ask For Help**

You can bring a support person with you to appointments. This person could be a friend, family member, or support worker. They can help you talk to your doctor, ask questions, and take notes.

If you have been waiting many weeks or months to hear back from a service or clinic, you can call or email them to ask for an update. Ask the staff when they will next contact you and make a reminder to call or email them on that date.

## **Write Things Down**

Before your appointment, you can make a list of questions or topics you want to talk about with your doctor. You can give this list to your doctor or use it to remind you. If your list is long, put the most important things at the top.

During your appointment, write down the important things your doctor says. Write down any other doctors or places you might need to go to. It's okay to ask your doctor to slow down or repeat things so you can write it down. You can also ask your doctor to write the information for you.

"It's kind of hard for me to see the things that I do myself. And it's hard for me to advocate for myself. Because my partner gets an external point of view, it's easier for her to speak sometimes when health care providers ask questions, and I don't know the answer to them. I think that has been helpful for both me and my doctors." –Avery

## **Coming Out**

It's okay to feel nervous to tell a doctor that you're autistic. You don't have to tell them if you don't want to. Remember, you can change your mind later. You can also tell your doctor what you need, even if you don't say that you are autistic. Like if bright lights bother you, if the hospital makes you nervous, or if you need information written down to remember. You can also tell your doctor your name and pronouns, even if you don't tell them everything about your gender.

## **Self-Advocacy**

## **Advocating for Yourself**

You can ask for the supports that you need to access health care. These are called accommodations. There are tools at the end of this document that can help you ask doctors for what you need.

If your doctor doesn't help or respect you, you can switch to a different doctor. But sometimes there are not enough doctors and you would have to wait a long time for a new doctor. Do your best to advocate for yourself with your current doctor. You deserve health care that meets your needs and respects who you are!

Advocating for yourself can be hard and tiring. If you can't communicate your needs during an appointment, you can always say something next time. It's also okay if you don't say anything when a doctor says something harmful. You know best what you need to be safe.

"If parts of the process are inaccessible to you, get the supports and accessibility things you need." - Spencer

"I want more
autistic people to be
empowered, to
make their own
choices, and to
think for
themselves
strategically." -Ivan

"I would just encourage people to make their own decisions and to have conversations with friends, with their doctors. Ask a lot more questions and not be afraid to do something that others around them, including doctors, wouldn't consider doing." -Jay

## When Things Go Badly

This document can help you advocate for yourself, but some people may still treat you badly. Sometimes, doctors don't understand or believe autistic people. Some people still have harmful and wrong ideas about trans autistic people. This is not your fault. You have the right to respectful health care that meets your needs. If you had very bad or unfair care, you can make a formal complaint. In Ontario, talk the <u>Patient Ombudsman</u> for more information.

## **Finding Community**

## **Peer and Community Support**

You can get lots of help and information from other trans autistic people. There are groups for trans and autistic people on social media and other websites. You can ask in these groups for suggestions of doctors who are good with trans autistic people. For example, there are Facebook groups called <u>"Autistic & Trans"</u> and <u>"Actually Autistic and Trans – No Gatekeeping."</u>

In Ontario, the Reddit forum <u>r/TransOntario</u> is a good place to ask questions and talk to other trans people. There is also a group of autistic activists in Canada called Autistics For Autistics (A4A). <u>The A4A website</u> has a link to their Facebook group. The Facebook group also has a link to their Discord server for autistic adults in Canada.

You can also look for support groups for trans people near you. They might be at an LGBTQ+ centre, sexual health clinic, youth clinic, or community health centre.

"One thing that really helped me was relying on community and making sure that the people that you're surrounding yourself with are people that are willing to fight alongside you and can support you and can share intersectional identities and share that need for change." - Mason

"My advice would be to seek out those communities because that's the best resource to get you through until you can find the therapists and doctors and nurses that you are comfortable with and who can provide you with care in a good way." – Molly

"It really comes down to the communities that you have access to to build you up so that you can be yourself." – Ivan

#### **Additional Resources**

## More Information About Gender-Affirming Care

Rainbow Health Ontario has a <u>Trans Health Knowledge Base</u> of common questions about gender-affirming care in Ontario.

<u>Trans Care BC</u> has information about hormones. The UCSF Transgender Care program also has more detailed information on <u>testosterone</u> and <u>estrogen</u>.

There is information about surgery from <u>Trans Care BC</u> and <u>Rainbow Health Ontario</u>.

In Ontario, Rainbow Health Ontario has a <u>service provider directory</u> of doctors, clinics, and other service providers that have experience helping LGBTQ+ people. You can also search for LGBTQ+ resources on the <u>211 website</u> or by phoning 2-1-1.

## More Tips for Self-Advocacy

YouthCO created a website called <u>Navigating Healthcare</u>: A <u>Gift of Community</u> <u>Wisdom</u>. It shares advice and ideas on navigating healthcare systems. It includes strategies for self-care and community care before, during, and after appointments.

Spectrum Intersections created a <u>guide to self-advocacy in health care for LGBTIQA+</u> <u>autistic people</u>. There is a plain language and easy language version. It also has personal info cards that you can give to doctors to help them support you.

AASPIRE has information and worksheets about health care for autistic people.

Trans Care BC has a <u>self-advocacy guide</u> for health care referrals.

<u>Surrey Place</u> and <u>AIDE Canada</u> have worksheets to help you make notes before, during, and after an appointment.

## **Author and Copyright Information**

This resource was developed in 2024 by Kai Jacobsen based on their MA in Sociology thesis research. You can contact them at <a href="mailto:KaiJacobsen@cmail.carleton.ca">KaiJacobsen@cmail.carleton.ca</a>. Their thesis research was supported by a Canada Graduate Scholarship - Master's from the Social Sciences and Humanities Research Council, an Ontario Graduate Scholarship, and an Autism Scholars Award from the Council of Ontario Universities. This document is licensed under CC BY-NC-ND 4.0.