

Your Journey with Giant Cell Arteritis



For more information scan this QR code or go to myhealth.alberta.ca/gca-pathway

Giant cell arteritis (GCA) is an inflammatory condition that affects your blood vessels. GCA (also known as temporal arteritis) causes a narrowing of the arteries that carry blood to your head, neck, and chest. This means that people who have GCA need to be treated right away to avoid serious issues such as vision loss or stroke. You are the most important part of your healthcare team. This guide will help you to know what to expect as you work with your team to manage and treat GCA. If you have any questions along the way, please ask your healthcare team. Click on the page numbers in blue if you want more information about the step in your journey.

Before your appointment ([page 4](#))

- Write down how you feel, your symptoms, and any questions or concerns.
- Consider bringing a family member or friend to support you.



Visit your healthcare provider ([page 6](#))

- Share all of your symptoms and concerns. Your health includes physical, emotional, spiritual, financial, and social elements.
- In order to better manage your health condition, your healthcare provider needs to hear from you and understand who you are and what matters to you.



Get your tests ([page 8](#))

- Your healthcare provider will need bloodwork to check if there is inflammation in your body.
- If your healthcare provider is concerned that you might have GCA, you may also go for an ultrasound or a biopsy.



Review your test results ([page 8](#))

- Find your test results on MyHealth Records or MyChart (myhealth.alberta.ca/myhealthrecords or ahs.ca/mychart) or ask your healthcare provider to print them for you.
- Talk with your healthcare provider so you know what your test results mean.



Review your treatment & management options ([page 10](#))

- Your healthcare provider will help you better understand your condition and give you important strategies to guide your recovery.
- Medication will be used to treat GCA and steroids may be started by your healthcare provider after reviewing your test results. It will be important to start medication early.
- Discuss with your healthcare provider what to expect from the treatment, how any side effects may impact you, and how to manage them.



Start your treatment & watch your symptoms ([page 11](#))

- Take an active role in your treatment.
- Watch for changes in your health and contact your provider about any new symptoms.



Talk with your healthcare provider about a referral ([page 12](#))

- If your healthcare provider thinks there is a risk of GCA, you will be referred to a rheumatologist.
- Ask who you are being sent to and what they do.
- You should hear from a rheumatologist within a few days from being referred.



Keep taking care of yourself ([page 13](#))

- Keep taking care of your overall health.
- Look for other healthy lifestyle resources and supports.



Whole-person health
([page 2](#))

Important Tips:

Need to connect with a primary care clinic?

ahs.ca/findadoctor

Need a translator or interpreter? Let your healthcare provider know

Need health advice?

Call Health Link at 811

Need to find programs and resources in your community?

Call 211 or visit ab.211.ca



Primary Care
Alberta

How to use this resource

The information provided in this resource is based on validated evidence from a variety of sources, including healthcare professionals in Alberta, peer-reviewed journals, current clinical guidelines, validated patient resources, and specialty care recommendations. It is intended as general health information and should not replace the clinical judgment or advice of a qualified healthcare provider. This resource does not address the unique needs of individual patients. Always consult with your healthcare team and follow their recommendations for your specific care.

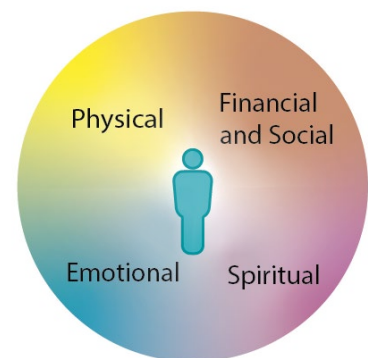
These pages are for you to use as needed. You can look through all of them at once or just the ones that help you now. Feel free to come back to the resource whenever you need it.

Whole-person health

The whole-person health approach will help you and your healthcare team better manage your health condition. It is drawn from the teachings of the medicine wheel.

Whole-person health means thinking about all parts of your health and wellness: physical, financial and social, spiritual, and emotional. All of these parts are connected and influence each other. It's important to be aware of your personal needs in each part and to share that information with your healthcare team.

- **Physical:** your specific health conditions and how well your body works
- **Financial and Social:** your ability to meet your housing, transportation, food, and health needs, feeling supported to manage your daily life, and having meaningful relationships
- **Spiritual:** your beliefs, sense of connection, and purpose
- **Emotional:** how you think, feel, and cope with life events



Whole-person health

Whole-person health also reminds us that we are all connected and work together: you, your support systems, and your healthcare providers. Your healthcare providers could be your doctor, nurse practitioner, or a team that comes together with you to plan and organize your care.

Your healthcare provider needs to understand who you are and what matters to you. This helps to build trust. But it can be hard to know what to share or what to say. Try starting by asking yourself:

“What are the things in my life that are important to me?”

“What are the things in my life that may be affecting my health and well-being?”



Bringing forward what matters to you is important. Here are some examples of things you may want to talk about with your healthcare provider:

Physical

“My symptoms are making it hard for me to do my job.”

“Because of my pain and how hard it is for me to move around, it’s hard to take care of myself.”

Financial and Social

“I’m worried I won’t be able to get to all of my appointments.”

“I need my daughter with me as a translator.”

“I’m not sure how I will pay for my medications this month.”

Emotional

“I’m lonely and have no one to talk to.”

“I have a lot of stress and I’m not sure how to manage it.”

“Ever since my friend died, I’ve been struggling with my feelings.”

Spiritual

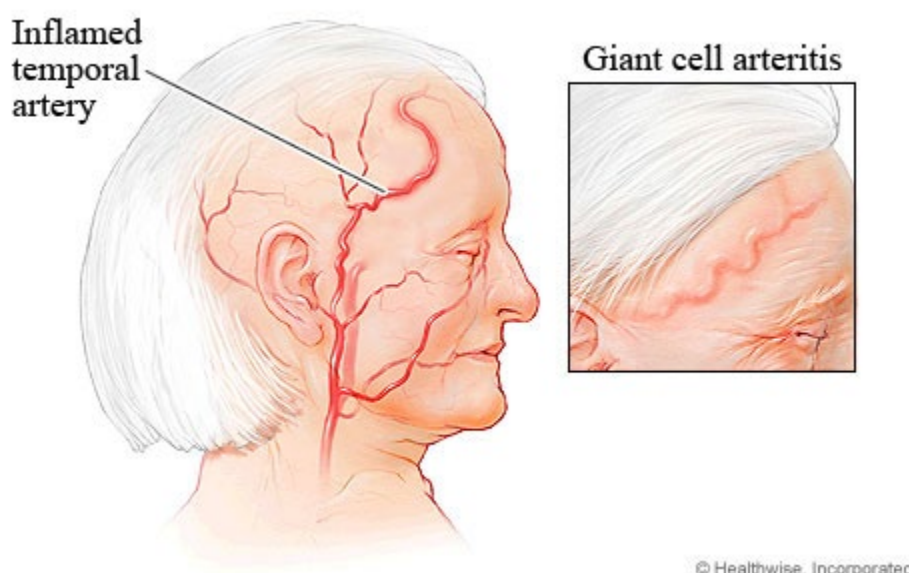
“It’s important that I follow traditional healing practices.”

“How can I include my culture’s foods and family recipes in my nutrition plan?”

“It’s important that my religious practice of fasting is respected and brought into my care.”

What is giant cell arteritis?

Giant cell arteritis (GCA) is an inflammatory condition affecting your blood vessels, causing them to narrow. GCA is one example of a group of health conditions called vasculitis. The narrowing of the arteries can prevent the blood from flowing to your head, neck, and chest which can lead to vision loss or a stroke. GCA affects people over the age of 50 and is commonly seen in people with other inflammatory conditions such as polymyalgia rheumatica, which is a condition that causes pain and stiffness in the neck, shoulders, and hips.



Before your appointment

Everyone will have their own unique journey with GCA. How you move through your journey, the number of visits with your healthcare team, the steps you will take, and the order you take them in will depend on your individual needs and will be decided in partnership with your healthcare team. Always follow the specific recommendations from your healthcare team, especially around how best to treat the condition.

Here are a few tips to help you get ready for your appointment with your healthcare provider:

- Consider using a symptom tracker to write down important information to share with your healthcare team about your symptoms.
- A symptom tracker can help you remember what symptoms you're feeling, when it started, how often it happens, and what makes it better or worse.

- Write down a list of your questions and concerns. When you're done, read your list and mark the most important things.
- Make a list of the prescription and non-prescription (over-the-counter) medicines you use, including any vitamins, herbs, and supplements.
- Ask someone you trust to go with you to your appointment. They can help you ask questions, write down instructions, and remember explanations.



Helpful tools and resources

- Use a **symptom tracker**: hqa.ca/symptom-tracker (Health Quality Alberta)
- To get the most out of your visit, plan to write notes during the visit or see the Alberta Health Services **My Care Conversations app** (ahs.ca/careapp) website for more information about recording your conversation with your healthcare provider.



Visit your healthcare provider

Your healthcare provider will review your history and symptoms. They may ask you questions to better understand what you are experiencing such as whether you have any tenderness around your temporal artery (between your eye and your ear) or around your scalp.

Your healthcare provider may also perform some assessments to help reach a diagnosis.

Tests and assessments may include:

Blood pressure and pulse taken on both arms

- This is an important way your healthcare provider can check for any narrowing of the blood vessels.
- Your healthcare provider will use a blood pressure cuff and a stethoscope to listen to your blood pressure and your pulse in both your arms.

Visual field testing

- GCA can often affect your vision, so it is important that your healthcare provider checks your eyes.
- Visual field testing measures your vision and how well you are able to look above, below and to the side of something you are looking at. It is not invasive and just involves you looking at an object or a light and telling your provider what or when you see it.

Checking for abnormal sounds in neck and groin arteries (bruits)

- This helps your healthcare provider check for narrowing in your arteries.
- Your healthcare provider will simply place a stethoscope over arteries in your neck and your groin to listen to what they sound like.

Neck, shoulders, and hip assessment

- GCA is often seen with other conditions such as polymyalgia rheumatica, which can cause pain and stiffness in your neck, shoulders, and hips.
- Your healthcare provider will feel how your neck, shoulders, and hips move to help them assess for any reduced range of motion or pain with movement.

What should I watch for (symptoms of concern)?

Contact your healthcare team if you have any of the following:

- Jaw pain and stiffness (pain in your jaw that is brought on with prolonged chewing and that feels better with rest)
- Scalp tenderness
- Changes to your vision (blurred vision, double vision, vision loss)
- Slurred speech



- New onset of headache (that is not relieved by over-the-counter medication and lasts more than 24 hours)
- New onset of arm or leg pain with exercise, that gets better with rest
- Pain and stiffness to your neck, shoulders or hip (more than 1 hour of morning stiffness)

Contact your healthcare team if you have any other concerns that you want to be addressed.

What should I share with my healthcare provider?

- What impact the health condition or issue is having on things that are important to you, like your job, hobbies and interests, and relationships.
- What has worked for you in the past to manage your current condition.
- What types of things help you work better with your healthcare team and what you expect and need from the relationship with your healthcare provider.
- There are lots of things in your life that can impact your ability to manage your health, like:
 - Problems with money, housing, and access to transportation
 - Alcohol or drug use
 - Not enough support or help
 - Childhood experiences

It's important to talk about these things with your healthcare provider because they all play a role in your health and well-being.

You are the most important part of your healthcare team.

If you don't understand what your healthcare team is telling you, let them know right away. Be open and honest. You might say:

"This is new to me. Could you please explain it slowly, using language that is easier to understand?"

"It sounded like you said that I should... Did I understand that correctly?"

"Can you show me a picture or model to help me understand?"



Helpful tools and resources

- Making the most of your appointment: myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=hw226888
- Working with your healthcare team: hqa.ca/info (Health Quality Alberta)



Get your tests

Bloodwork

An important part of diagnosing GCA is testing your blood for signs of inflammation. Specifically, your C-reactive protein (known as CRP) will show if there is inflammation in your body. The results of this are needed to help decide on how to manage your condition.

Temporal ultrasound

Your rheumatologist may send you for an ultrasound of your temporal artery. A temporal ultrasound is a test where sound waves create a picture of the blood vessels in your head, neck, and sometimes armpit to check for inflammation. It's a quick and painless way to see if you have giant cell arteritis.

Temporal artery biopsy

Your rheumatologist may send you for a temporal artery biopsy, which is a minor surgical procedure where a small piece of a blood vessel, called the temporal artery, is taken out to test for inflammation. The temporal artery is located on the side of your head, near your temple. You will have a small scar after the procedure.



Review your test results

It is important to know what your test results are and what they mean for you personally. Take time to discuss your results with your healthcare provider. Medical terms can be hard to understand. And even common words like “positive” or “negative” might mean something different for medical tests. Ask your healthcare provider for explanations and examples to make sure you fully understand.

You might ask:

“What does this mean for me?”

“Is there a current concern? If so, what is it?”



Helpful tools and resources on next page.





Helpful tools and resources

You may find some of your results and health information using secure online tools:

MyHealth Records

See your lab results, immunizations, and some other results with a MyHealth Records account. Sign up at myhealth.alberta.ca/myhealthrecords.

MyChart

See your health information, manage your Alberta Health Services appointments, and interact directly with some members of your healthcare team. Ask your healthcare provider how to access your MyChart account. Learn more at ahs.ca/mychart





Review your treatment & management options

Every individual will require their own specific treatment and management plan. Always follow the specific recommendations from your healthcare team.

Steroid medication

If you have a moderate to high risk of GCA, your healthcare provider will start you on a steroid medication called prednisone which is intended to reduce inflammation. Your healthcare provider will discuss the potential side effects and risks of this medication but starting medication early is very important in treating GCA.

Other treatment options

Your healthcare provider may also try to prevent side effects that are commonly seen with steroid use, such as reducing the risk of osteoporosis (weakening of your bones), reducing your cardiovascular risk (damage to your heart and blood vessels) and preventing stomach ulcers.

Asking the following questions can help you make an informed decision about your different treatment options and decide which one(s) will work best for you:

“What are the advantages and disadvantages of each option?”

“Can I use any of these options together?”

“How will this make me feel? Will it have side effects?”

“What results can I expect?”





Start your treatment & watch your symptoms

As you begin your treatment, remember that if something doesn't work the way you thought it would, talk with your healthcare provider to try and find the best solution.

Prednisone is critically important for the treatment of GCA but can have several side effects. These include stomach upset, high blood pressure, high blood sugar levels, mood changes, and can weaken your bones. Talk to your healthcare provider about these possible side effects and how best to manage them.

Watch closely for changes in your health, and be sure to contact your healthcare provider right away if you start experiencing:

- Jaw pain and stiffness
- Scalp tenderness
- A return, or a new onset of headache (that is not relieved by over-the-counter medication and lasts more than 24 hours)
- A return, or new onset of arm or leg pain with exercise, that gets better with rest
- Pain and stiffness to your neck, shoulders or hip (more than 1 hour of morning stiffness)

If you notice any new changes in your vision, like blurriness, double vision, or vision loss, go to the nearest emergency department straight away.

Call **911** if you have:

- Sudden numbness or weakness in your face, arm, or leg
- Sudden confusion or trouble speaking
- Sudden severe headache

Watching your symptoms is important. Call your healthcare provider or Health Link at 811 if you have any concerns. You might feel like you don't want to bother your healthcare team, but no detail is too small to share. If it matters to you, it will matter to your healthcare team.

You can clarify with your healthcare team what to expect in terms of follow-up communication. Connect with your healthcare team whenever you:

- Have questions
- Notice your symptoms getting worse
- Have problems with your medicine
- Haven't gotten test results or heard back about an appointment in the time you had agreed to



Helpful tools and resources

If you can't reach your healthcare provider and need health advice or information, call Health Link anytime, day or night, by dialing **811**.





Talk with your healthcare provider about a referral

If your healthcare provider thinks there is a risk of GCA, you will be referred to a rheumatologist.

The role of a rheumatologist is to help you manage your condition by selecting the most appropriate tests and what medication to be on. You should hear from a rheumatologist within a few days from being referred and they will then manage your condition from that point on.

You may also be referred to a diagnostic imaging centre for an ultrasound or to a surgeon for a biopsy of the artery on the side of your head (temporal artery).

You can find out more about the referral criteria for a specialist by asking your healthcare provider.



Helpful tools and resources

To learn about how to prepare for your specialist appointment, check out the QuRE Patient and Caregiver Journal by visiting ahs.ca/qure.





Keep taking care of yourself

There are many different things that can impact your health and wellness. It is important to be able to work with your healthcare team to decide what is best for you, in your life, given your own unique circumstances as you manage GCA.

Remember, you don't need to do everything all at once. Take realistic and manageable steps in your health and wellness. Consider if any of the following lifestyle changes may be beneficial to discuss with your healthcare provider:

- Strategies for good sleep habits or routines to help you sleep better.
- Reviewing your nutrition habits to see if there are foods that you can add in or cut down on to help balance your diet.
- Improving hydration to ensure your body has the right amount of water each day.
- Limiting the amount of caffeine that you drink in a day.
- Regular low intensity exercise. Where possible, supervised exercise (with a physiotherapist, kinesiologist, or personal trainer) can help ensure that the level of exercise you are doing will best fit to your health needs.
- Relaxation techniques such as yoga, meditation, or breathing exercises can help with whole-person wellness.
- Pacing your daily activities to help spread out what you need to get done in a day which can help to avoid burning out and triggering new symptoms.



Helpful tools and resources

Find programs and resources in your community:

211 connects Albertans to the programs and resources they need, anytime, day or night. Whether you're looking for help with mental health, financial assistance, basic needs or other challenges, 211 is here to help you find supports. It's free, confidential, and available in over 170 languages by phone, making it easy to access help when you need it.

To connect with **211 Alberta**:

- Call 211
- Text INFO to 211
- Chat or search at ab.211.ca

The **Alberta Healthy Living Program** offers free workshops, classes, and supervised exercise and nutrition services to adults living with a variety of chronic conditions and diseases. Many education classes and workshops are available province wide. Learn more by visiting ahs.ca/ahlp.

Chronic Disease Management support: ahs.ca/cdm

Health information & tools: myhealth.alberta.ca/Pages/HealthInfoToolsDefault.aspx



Resources

There's lots of information out there, and it can be confusing to know what information is accurate and true. Here are some great resources about GCA that may be helpful for you.

- [Giant Cell Arteritis \(myhealth.alberta.ca\)](http://myhealth.alberta.ca)
- [American College of Rheumatology \(rheumatology.org\)](http://rheumatology.org)
- VasculitisFoundation.org
- [Polymyalgia Rheumatica with GCA \(arthritis.ca\)](http://arthritis.ca)
- [Trigeminal neuralgia \(myhealth.alberta.ca\)](http://myhealth.alberta.ca)

Get help now:

- Emergency: Call 911
- Health Link: Call 811

Mental health, addiction, and crisis support:

- 811 or [Addiction Helpline](http://AddictionHelpline): 1-866-332-2322
- 811 or [Mental Health Helpline](http://MentalHealthHelpline): 1-877-303-2642
- Crisis Text Line: Text CONNECT to 741741
- Crisis Services Canada: 988, or visit talksuicide.ca
- Office of Mental Health Patient Advocates: alberta.ca/office-of-alberta-health-advocates.aspx

Helpful tip

If you can't print this resource at home, ask a family member, friend, or your healthcare provider to print it for you. You can also use a computer and printer at your local library.

Community and social supports:

- 211 Alberta: Call 211, or visit ab.211.ca
- Family Violence Info Line: 310-1818, or visit alberta.ca/family-violence-find-supports.aspx
- Income Support: 1-866-644-5135, or visit alberta.ca/income-support.aspx

Alberta Health Services programs:

- Home Care: ahs.ca/homecare
- Find a Dietitian: ahs.ca/nutrition
 - Health Link has dietitians to answer nutrition questions. Call Health Link at 811 and ask to talk to a dietitian or complete the self-referral form on ahs.ca/811.
- Spiritual Care Services: ahs.ca/spiritualcare

Primary care (family doctors and nurse practitioners):

- Find a doctor or nurse practitioner: ahs.ca/findadoctor
- Virtual care guide: ahs.ca/virtualhealth

Patient concerns and feedback:

- Office of Alberta Health Advocates: alberta.ca/office-of-alberta-health-advocates.aspx
 - Offers coaching to help you advocate for yourself in the health system, and support to learn how the health system works and how to navigate through it.
- Alberta Health Services Patient Relations: 1-855-550-2555, or visit ahs.ca/patientfeedback



Important phone numbers

Name or clinic name:

Phone number:

Name or clinic name:

Phone number:

Name or clinic name:

Phone number:

Notes

Use this space to take notes.

About this Pathway

The Provincial Pathways Unit co-developed this patient pathway in partnership with patient and family advisors, primary and specialty care providers in Alberta. It is current as of August 2024.

Authors & Conflict of Interest Declaration

This pathway was reviewed and revised by a multi-disciplinary co-design team including rheumatologists and primary care providers from across Alberta.

Pathway Review Process

Patient pathways undergo scheduled review every three years, or earlier if there is a clinically significant change in knowledge or practice. The next scheduled review is August 2027. However, we welcome feedback at any time. Please send your [feedback here](#), or email us at albertapathways@primarycarealberta.ca.

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Disclaimer

This pathway represents evidence-based best practice but does not override the individual responsibility of healthcare professionals to make decisions appropriate to their patients using their own clinical judgment given their patients' specific clinical conditions, in consultation with patients/alternate decision makers. The pathway is not a substitute for clinical judgment or advice of a qualified healthcare professional. It is expected that all users will seek advice of other appropriately qualified and regulated healthcare providers with any issues transcending their specific knowledge, scope of regulated practice, or professional competence.