

CARING FOR A LOVED ONE WITH C3G

As a caregiver, you play a vital role in helping your loved one manage and live with C3G. Remember, you are not alone. This guide will give you tips and help you find resources so you can navigate this journey.

C3G, complement 3 glomerulopathy.

Approved Use

What is FABHALTA?

FABHALTA is a prescription medicine used to treat adults with a kidney disease called complement 3 glomerulopathy (C3G), to reduce protein in the urine (proteinuria).

It is not known if FABHALTA is safe and effective in children with C3G.

Important Safety Information

What is the most important information I should know about FABHALTA?

FABHALTA is a medicine that affects part of your immune system and may lower your ability to fight infections.

- FABHALTA increases your chance of getting serious infections caused by encapsulated bacteria, including *Streptococcus pneumoniae*, *Neisseria meningitidis*, and *Haemophilus influenzae* type b. These serious infections may quickly become life-threatening or fatal if not recognized and treated early.

Please see additional Important Safety Information throughout and on [pages 8-9](#), and full [Prescribing Information](#), including [Boxed WARNING](#) and [Medication Guide](#).



Patient and caregiver portrayal.



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YOUR ROLE AS CAREGIVER IS CRUCIAL

A C3G diagnosis can be life-changing for your loved one, your family, and yourself. A supportive caregiver plays an important role in a patient's disease journey

If your loved one has C3G, this means you play the role of caregiver for a patient with an ultra-rare disease. Questions may swirl through your mind, and struggles may come along the way, but we're here to help you find guidance, tips, and resources to help along the way.



Your role as a caregiver

Remember, you play a vital role in a loved one's disease journey. Your responsibilities may include helping them to:

- Understand the impact of their diagnosis
- Manage their treatment, including keeping track of lab results
- Navigate life with a rare disease
- Ease their fear and empathize with their feelings
- Make necessary changes in their diet

Know where to look for help

You're probably exposed to a lot of information about C3G, but questions may still persist. For answers and more information, seek support from members of your loved one's care team and the C3G community.



Caregiver portrayal.

MANAGING YOUR OWN WELL-BEING

Know the signs of stress and burnout

Keep in mind that as a caregiver you may be facing added pressure, demands, and responsibilities. They add up and can lead to stress and burnout. Believe it or not, keeping yourself healthy can be crucial in order to provide the best care for your loved one.

Caregiver burnout is real, so please take the time you need for yourself. It's important to know what signs to watch for and when to reset to give yourself renewed energy.



Signs of stress

- Feeling overwhelmed, worried, sad, or alone
- Sleeping too much or not enough
- Withdrawing from friends and family or activities you once enjoyed
- Becoming easily irritated or resentful
- Changes in eating habits and/or drinking too much



Signs of burnout

- Overwhelming exhaustion
- Can't concentrate
- Disinterest in anything or low energy levels
- Inability to relax
- Frequent sickness

DID YOU KNOW?

Rare-disease caregivers spend an average of 12 more hours per week providing care compared to caregivers in general. Finding support, accepting help, and checking in with yourself can be important moving forward.

Important Safety Information (continued)

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 - You must complete or update your vaccinations against *Streptococcus pneumoniae* and *Neisseria meningitidis* at least 2 weeks before your first dose of FABHALTA.

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HELPFUL TIPS FOR SELF-CARE

Monitoring and attending to your own needs can be crucial for any caregiver, especially those dealing with a rare disease

Unfortunately, there may be times when fulfilling all your duties as a caregiver can feel overwhelming. Take stock of yourself and maintain your mental, physical, and emotional health.

Some tips to abide by:



Get plenty of sleep—7 to 8 hours per night if possible



Take time for yourself each day, and tend to your own interests or hobbies, even for just a few minutes



Lean on your community, talk to a friend, and accept support from other caregivers or support groups



Keep up with your own medical needs, such as making regular doctor and dentist visits

Remember, you're not in this alone

In addition to joining a support group, you can also [click here](#) to find additional resources to learn more about C3G.

Important Safety Information (continued)

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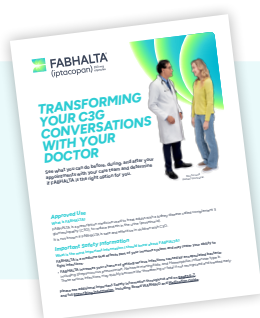
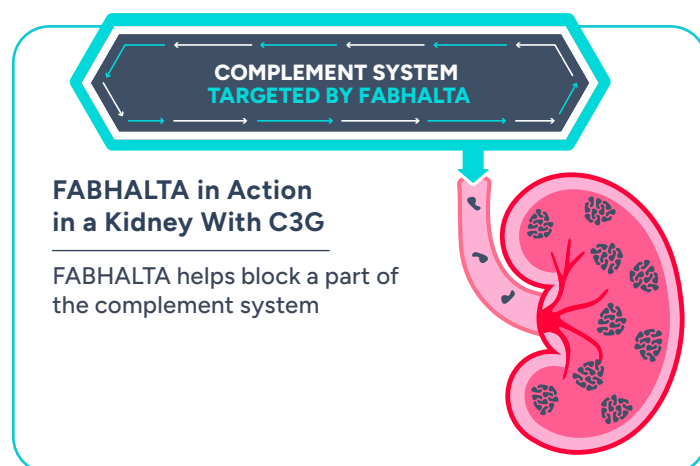
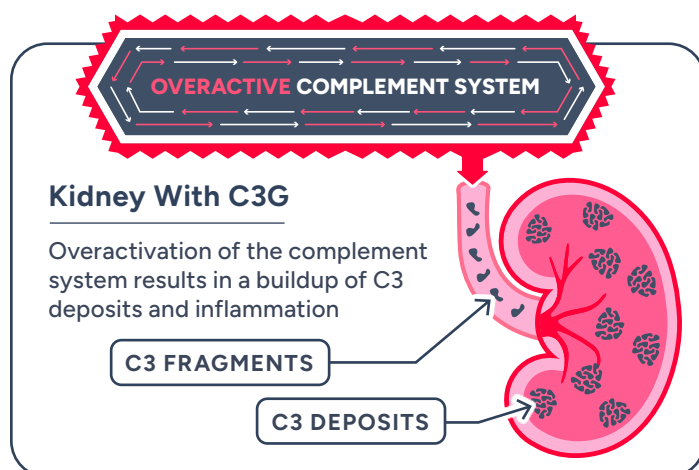


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UNDERSTANDING C3G AND HOW FABHALTA WORKS

You may feel overwhelmed with information and unsure where to begin. Learning about C3G and the changes it can bring is a good place to start.

In complement 3 glomerulopathy (C3G), the complement system (a part of your immune system that helps fight infections) becomes overactive, resulting in a buildup of C3 in your kidneys as well as inflammation.



You and your loved one should talk to your loved one's doctor about C3G and the concerns you may have. **Read or download the FABHALTA Doctor Discussion Guide.**

Important Safety Information (continued)

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HELPFUL LIFESTYLE RECOMMENDATIONS

Help create lasting changes in their daily routine

Your loved one with C3G will likely need to make a few key lifestyle changes and adjust their daily routine. **These changes could include:**



Modifying their diet to incorporate more kidney-healthy ingredients and limit their salt intake. Talk to a doctor or dietitian about optimal dietary changes



Implementing a regular exercise routine



Helping manage their medication schedule



Contacting their health care provider if you believe that your loved one is experiencing any side effect

As the caregiver, some things you can do to make these changes easier are:

- Assist and encourage your loved one to follow a healthy lifestyle
- Help them keep track of their diet and find expert nutrition advice if necessary
- Encourage them to get regular physical activity and maintain a healthy weight
- Keep a lookout for any signs that they may be getting sick

Important Safety Information (continued)

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- Vaccines do not prevent all infections caused by encapsulated bacteria. **Call your health care provider or get emergency medical care right away if you have any of these signs and symptoms of a serious infection:**

- | | | | |
|---|----------------------|---|--|
| ▪ Fever with or without shivers or chills | ▪ Headache and fever | ▪ Fever with breathlessness or fast breathing | ▪ Headache with stiff neck or stiff back |
| ▪ Fever with chest pain and cough | ▪ Confusion | ▪ Headache with nausea or vomiting | ▪ Body aches with flu-like symptoms |
| ▪ Fever with high heart rate | ▪ Clammy skin | | ▪ Eyes sensitive to light |
| | ▪ Fever and rash | | |

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HELPING THEM FIND SUPPORT



Connecting with a C3G community

Having a rare disease can feel lonely sometimes. However, helping your loved one connect with a C3G community of people who are going through a similar experience can give them a space to share their challenges, struggles, and victories.

Organizations bring people together to share information and stories in the form of support groups, which can provide helpful benefits including:

- Conversations with people who understand what you are going through
- Tips for managing the day-to-day of living with C3G
- Empowerment and support from people with similar experiences

Organizations you may find helpful include NephCure and the American Kidney Fund.*

Additionally, you could search social media sites for support groups that may help.

*The organizations and websites listed are independently operated and are not managed by Novartis Pharmaceuticals Corporation. Novartis assumes no responsibility for any information they may provide.

DID YOU KNOW?

C3G is an ultra-rare disease, affecting only 2 to 3 out of every 1 million people. In such a small community, connecting with others can have a meaningful impact.

Important Safety Information (continued)

What is the most important information I should know about FABHALTA? (continued)

Your health care provider will give you a Patient Safety Card about the risk of serious infections. Carry it with you at all times during treatment and for 2 weeks after your last dose of FABHALTA. Your risk of serious infections may continue for a few weeks after your last dose of FABHALTA. It is important to show this card to any health care provider who treats you. This will help them diagnose and treat you quickly.

FABHALTA is only available through a program called the FABHALTA Risk Evaluation and Mitigation Strategy (REMS). Before you can take FABHALTA, your health care provider must:

- Enroll in the FABHALTA REMS program.
- Counsel you about the risk of serious infections caused by certain bacteria.
- Give you information about the symptoms of serious infections.
- Make sure that you are vaccinated against serious infections caused by encapsulated bacteria and that you receive antibiotics if you need to start FABHALTA right away and you are not up-to-date on your vaccinations.
- Give you a **Patient Safety Card** about your risk of serious infections.

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APPROVED USE AND IMPORTANT SAFETY INFORMATION FOR FABHALTA (iptacopan)

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 - If you have not been vaccinated and FABHALTA must be started right away, you should also receive antibiotics to take for as long as your health care provider tells you.
 - If you have been vaccinated against these bacteria in the past, you might need additional vaccinations before starting FABHALTA. Your health care provider will decide if you need additional vaccinations.

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Important Safety Information continues >>

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APPROVED USE AND IMPORTANT SAFETY INFORMATION FOR FABHALTA (iptacopan) (continued)

Who should NOT take FABHALTA?

Do not take FABHALTA if you:

- Are allergic to FABHALTA or any of the ingredients in FABHALTA.
- Have a serious infection caused by encapsulated bacteria, including *Streptococcus pneumoniae*, *Neisseria meningitidis*, or *Haemophilus influenzae* type b, when you are starting FABHALTA.

Before you take FABHALTA, tell your health care provider about all your medical conditions, including if you:

- Have an infection or fever.
- Have liver problems.
- Are pregnant or plan to become pregnant. It is not known if FABHALTA will harm your unborn baby.
- Are breastfeeding or plan to breastfeed. It is not known if FABHALTA passes into your breast milk. You should not breastfeed during treatment and for 5 days after your final dose of FABHALTA.

Tell your health care provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking FABHALTA with certain other medicines may affect the way FABHALTA works and may cause side effects.

Know the medicines you take and the vaccines you receive. Keep a list of them to show your health care provider and pharmacist when you get a new medicine.

What are the possible side effects of FABHALTA?

FABHALTA may cause serious side effects, including:

- See “What is the most important information I should know about FABHALTA?”
- **Increased cholesterol and triglyceride (lipid) levels in your blood.** Your health care provider will do blood tests to check your cholesterol and triglycerides during treatment with FABHALTA. Your health care provider may start you on a medicine to lower your cholesterol if needed.

The most common side effects of FABHALTA in adults include:

- Headache
- Nasal congestion, runny nose, cough, sneezing, and sore throat (nasopharyngitis)
- Diarrhea
- Pain in the stomach (abdomen)
- Infections (bacterial and viral)
- Nausea
- Rash

Tell your health care provider about any side effect that bothers you or that does not go away. These are not all the possible side effects of FABHALTA.

Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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SUPPORTING YOU THROUGH YOUR CAREGIVER JOURNEY

Novartis offers additional information and resources to help your loved one navigate C3G.

Visit [\[FABHALTA.com/C3G\]](https://FABHALTA.com/C3G) to learn more.

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