Know your TGs

Your health, your voice, your choice

A GUIDE TO SELF-ADVOCACY FOR PEOPLE WITH FAMILIAL CHYLOMICRONEMIA SYNDROME (FCS)

Eli, Living with FCS (and his mother Anne Marie)

Actor portrayal.
Not actual physician
or patient.

Take charge of your healthcare

Self-advocacy is the act of speaking up for your rights, needs, and preferences. It means standing up for yourself, making informed decisions, and taking an active role in your healthcare and overall well-being.

This guide is intended to provide you with tools to become a strong self-advocate when it comes to living with FCS, so you feel heard, respected, and supported.

The information provided here is for educational purposes only as a self-help tool and is not a guarantee of improved treatment.

Why self-advocacy matters for people with FCS

FCS is an underdiagnosed genetic condition, which means many healthcare professionals, family, friends, and others may not know about it. This lack of awareness can make it challenging to receive proper care and support.

By advocating for yourself, you can take better control of having your needs met and your condition taken seriously, instead of waiting for someone else to do it for you.

Actor portrayal.
Not actual patients.

The goals of self-advocacy

- Access to the right medical care and management options
- Increased awareness and understanding of your condition
- Fewer challenges in the home, medical environments, workplaces, and social settings
- More confidence in managing your condition and making informed decisions
- A strong support system that respects and supports your health journey

How you can be a strong self-advocate

1. **Educate yourself.** As someone living with FCS, you have to be an expert on your condition. Learn as much as possible about it, so you can make better decisions and advocate for your needs confidently.

2. **Communicate clearly and confidently.** Speak in a clear, calm, and assertive manner. Be direct but respectful to foster understanding and cooperation.

3. **Know your rights.** Knowing your rights means you can stand up for them. You may want to consider seeking legal assistance as needed to get what you deserve.

4. **Build a support system.** Connect with others who understand your condition, such as support groups, advocacy organizations, or trusted friends and family members. They can offer encouragement, resources, and assistance when advocating for yourself.

5. **Keep records.** Document important conversations, medical visits, and workplace interactions. This can help you track progress, remember key details, and provide evidence if needed.

Actor portrayal. Not actual physician or patient.

6. **Practice confidence and persistence.** Even if it is not your default personality, as someone with FCS, you will need to be firm and confident in your requests. Being firm, clear, persistent, and polite in having your questions answered–and your voice heard–can lead to more positive outcomes over time.

7. **Ask questions.** Request more information or seek clarification so you fully understand your options and decisions – especially when engaging with healthcare professionals.

8. **Be prepared.** Before appointments or discussions, plan what you want to say and what questions you need answered. Preparing notes or practicing beforehand can help you stay focused and articulate your needs effectively.

9. **Stay positive and solution-oriented.** Approach challenges with a problem-solving mindset. Instead of dwelling on obstacles, focus on potential solutions and ways to move forward.

10. **Seek help when needed.** If self-advocacy feels overwhelming, consider working with a family member or friend who can be a strong advocate. You may want to consider seeking out a professional patient advocate, legal advisor, or counselor who can assist in navigating complex situations.

Advocate for yourself in healthcare settings

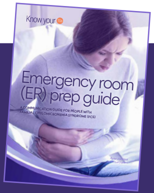
Since many healthcare professionals (HCPs) may not know about FCS, it will be up to you to educate them so you increase the chances of receiving the right care.

Be prepared.

- Bring a list of questions so all your concerns are addressed.
- Use the FCS CareBook from **KnowYourTGs.com** to track symptoms, medications, medical history, and more.
- Know as much as you can about FCS and related medical terminology, using resources like **KnowYourTGs.com** to educate yourself.
- Have a good idea of what you eat and drink regularly, including alcohol.

Explain FCS to HCPs who are unfamiliar with it.

- Give them information about FCS such as the "What is FCS?" flyer from the FCS CareBook and refer them to **TGAware.com**, a site made for HCPs.
- Use medical terminology related to the condition as much as possible to increase credibility.
- Describe how FCS affects you, using specific examples.
- Ask for specialist referrals when necessary.



Read the Emergency Room (ER) Prep Guide for people with FCS from KnowYourTGs.com.

The ER Prep Guide will not only prepare you for FCS-related ER visits but also has examples of how to talk effectively to HCPs that you can also use in non-emergency settings.

Understand your patient rights* and seek second opinions.

- Know about your rights to informed consent and access to specialists.
- Seek a second opinion if an HCP dismisses your concerns or seems wrong in their conclusions and recommendations.
- If hospitalized, seek support from Patient and Family Services, sometimes referred to as the hospital's patient advocate or ombudsman.
- Request clear explanations of all treatment plans before consenting.
- A lawyer may be able to help if HCPs or hospital staff fail to follow reasonable requests.

Run your healthcare team.

- Your HCPs work for you. Together, you should develop a treatment plan to help reduce your triglyceride levels. It should fit with other health problems and concerns you may have.
- Primary care includes the medical professionals you see for most routine medical visits. They may send you to specialists due to your FCS and the symptoms you experience.
- Specialists focus on treating specific conditions, such as lipid specialists (lipid conditions), cardiologists (disease of the heart and blood vessels), and endocrinologists (hormones and endocrine disorders like pancreatitis and diabetes).
- Registered dietitians and nutrition experts can create a personalized, FCS-friendly meal plan that is tailored to your specific tastes and dietary needs, rather than a generic plan.

Navigate insurance and treatment access.

- Understand your insurance coverage and appeal denied claims when necessary.
- Work with patient advocacy groups to access treatments and financial assistance.
- Stay informed about new treatment options and clinical trials.

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* Read the American Medical Association's Code of Medical Ethicss & Patient Rights at: https://code-medical-ethics.ama-assn.org/ethics-opinions/patient-rights

Advocate for yourself with friends and family

Explain FCS simply.*

Use clear, relatable language to help others understand your condition and its impact.

- Offer evidence-based explanations to those who want to see proof.
- Expect some resistance or skepticism from those with ingrained dietary beliefs.
- Be prepared to remind them about your condition more than once.

*** For detailed information on talking to friends and family of various ages, including example phrases to use, read A Communication Guide for People with Familial Chylomicronemia Syndrome or visit KnowYourTGs.com.**

Correct misconceptions.

Gently address misunderstandings and promote better awareness, such as:

- *"A little fat will not hurt."* Even a small amount of fat can cause serious health issues for someone with FCS.
- *"You just need to exercise more."* FCS is a genetic condition. I cannot manage it through exercise alone.
- *"You can take medication to fix it."* No current medication can cure FCS. A diet of less than 20 grams of fat per day is the primary way to manage it.

Actor portrayal. Not actual patients.

Set food boundaries.

Kindly but firmly communicate your dietary restrictions and ask for support in meal planning and gatherings.

- Bring your own food to social gatherings to ensure you have safe options.
- Politely decline foods that do not align with your dietary needs.
- Request modifications when eating out or attending family meals, but have safe food in case they won't make changes or you don't feel safe eating what they have.
- Prioritize self-care, even if it means missing certain activities that could put your health at risk.

Ask for support.

Let loved ones know how they can help whether by listening, learning, or offering encouragement. They can:

- Help prepare safe meals or keep FCS-friendly ingredients on hand.
- Understand if you need to leave social situations early or modify plans.
- Offer encouragement and comfort when managing FCS symptoms or feelings.
- Know what to do if you experience severe symptoms, such as recognizing signs of pancreatitis, and help you seek medical care if necessary.

Lead by example.

Your consistency in managing your health will reinforce the importance of self-care to those around you.

- Stick to your dietary and lifestyle choices to show others that your health needs are non-negotiable.
- Over time, they may come to respect and support your efforts as they see how crucial these choices are to your well-being.


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Advocate for yourself in the workplace

Only share as much as you are comfortable with.

You do not have to disclose your medical condition unless you need changes to a job or work environment due to your medical condition. If you choose to share, provide clear but concise explanations of how FCS affects your work.

Request reasonable workplace accommodations.

You may need flexible scheduling, dietary accommodations, or adjustments to workload to manage fatigue. Work with HR or management to develop a plan that meets both your needs and workplace expectations.

Understand your legal protections.

Learn about workplace protections such as the Americans with Disabilities Act (ADA) in the U.S. and similar laws in your area. Be prepared to provide medical documentation to support accommodation requests. Seeking advice from a lawyer or advocacy organizations is an option if your rights are not respected.

Manage stress and work-life balance.

Prioritize self-care by managing your workload and setting realistic expectations. Use stress management techniques such as mindfulness, scheduled breaks, or seeking support from workplace wellness programs.


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Advocate for yourself by building a support network

A strong support system can counter feelings of isolation so common with FCS. To create one:

- Look for people willing to listen and learn about your condition.
- Identify individuals who can provide practical help, such as meal planning, transportation, or advocacy in medical settings.
- Consider joining FCS-specific support groups or connecting with others who have similar experiences.

  Visit **KnowYourTGs.com** for a list of helpful links.

Once you have started building a support network:

- Be open and honest about your needs and how others can help you.
- Give them education about FCS so they understand the condition and its challenges.
- Set clear boundaries and expectations for the kind of support you need.
- Stay connected with your support system through regular communication, whether in person, by phone, or online.

As a member of the FCS community, you can:

- Be both a person who gets helped *and* helps others by receiving and sharing knowledge.
- Raise awareness about FCS through social media, local events, and support groups.
- Speak with policymakers about access to treatment and research funding.

NOTES

Visit **knowyourtgs.com** to learn more about about FCS symptoms, acute pancreatitis, genetics and more.

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