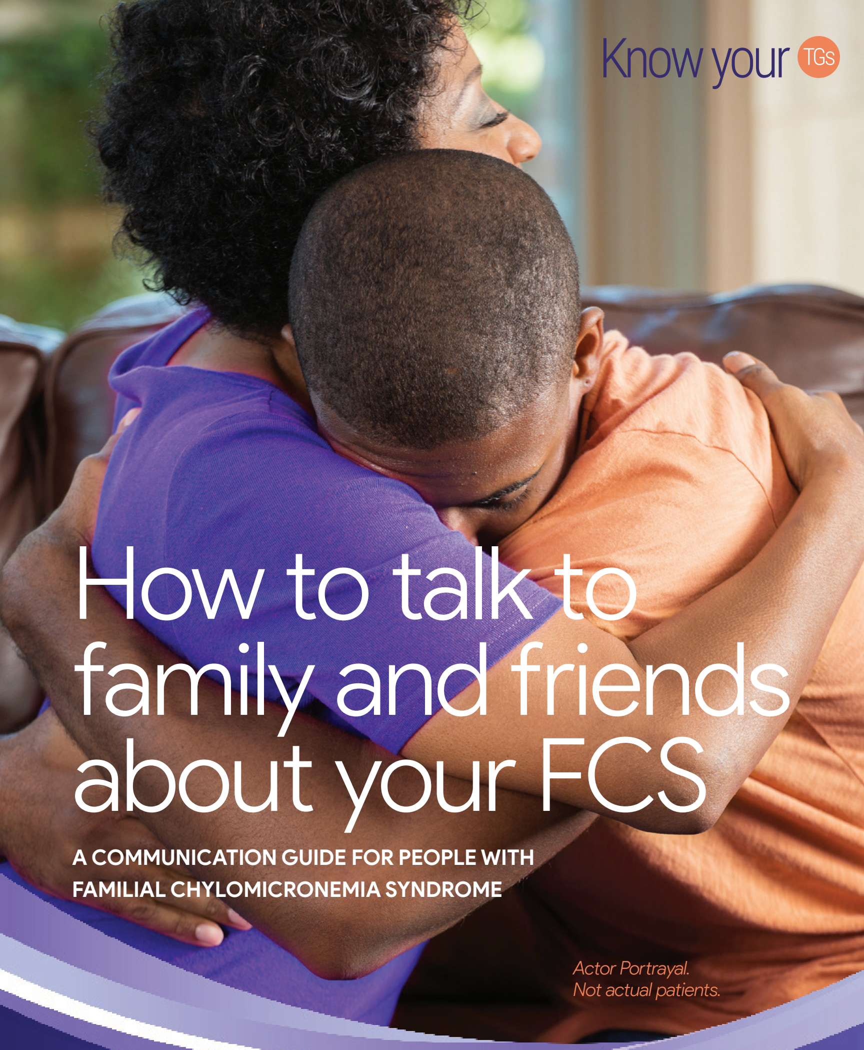
Know your TGs



Actor Portrayal.
Not actual patients.

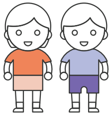
How to talk to family and friends about your FCS

A COMMUNICATION GUIDE FOR PEOPLE WITH FAMILIAL CHYLOMICRONEMIA SYNDROME

Age-appropriate explanations of FCS just got easier

This guide offers advice for communicating with different age groups based on how they typically process information. It includes examples of clear, supportive language that you might use to explain FCS, its dietary needs, and its impact on daily life.

Young children
(around ages 3-6)



SELF-CENTERED & EMOTIONALLY DRIVEN

How they process information

- Focused on how things affect them personally.
- Understand the world through play and imagination.
- Struggle with abstract ideas like genetics or long-term health.
- Have a simplistic and often magical understanding of illness, such as thinking it is punishment for wrongdoing.

How to talk to them

- Use simple, short, and concrete explanations that are not scary.
- Offer reassurance; they may fear a sick parent will “go away.”
- Use familiar metaphors, and dolls or food as props.
- Expect repeated questioning; repetition is how they learn.
- Normalize dietary differences and making positive choices.

Actor Portrayal.
Not actual patients.

Examples of how to talk about:

FCS and nutritional needs...

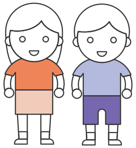
- *“My tummy doesn’t like certain foods. When I eat them, I feel bad, so I try to pick foods that help me feel good.”*
- *“Even though I have to be careful with food, we can still have fun together.”*
- *“Want to help me pick a yummy food that you like and my body likes?”*

Feeling bad or needing doctors/hosptalization...

- *“When my tummy feels bad, I need extra naptime to feel better. When I am done resting, we can play.”*
- *“I have to see a special helper called a ‘doctor’ who can help me feel better, but I will come back to you.”*
- *“Hospitals have extra tools to help me get better. While I’m there, you can draw me a picture, and I’ll keep it with me to feel happy.”*
- *“While I’m with the doctors, [this person] will take care of you. They will make sure you have fun and are safe.”*

School-age children

(around ages 7–12)



LOGICAL BUT LITERAL

How they typically process information

- Have begun to think logically but see things in black-and-white terms.
- Understand basic cause-and-effect, such as “If I eat this, I get sick.”
- Follow rules and may want to know what’s allowed and what’s not.
- Want to know why something happens.
- May have exposure to basic science.

How to talk to them

- Give clear, factual explanations without too much detail.
- Expect fairness questions like, *“Why can other people eat fat but not you?”*
- Let them help, since they like feeling useful and connected.

Examples of how to talk about:

FCS and your nutritional needs

- *“I was born with FCS and will always have it, like my eye color.”*
- *“Our bodies have helpers that break down food. One of mine doesn’t work, so I can’t eat a lot of fat.”*
- *“Fat is in foods like meat, butter, cheese, nuts, and oils. Most people’s bodies use fat for energy, but my body can’t break it down, so it just builds up in my blood until it makes me sick.”*
- *“You can help me by reminding me to check food labels or by picking out a healthy snack with me.”*

Unfairness

- *“I know it might seem unfair, but I’ve learned what foods are best for me. And there’s still so much I enjoy.”*
- *“Even though I have to be careful, I can still have fun.”*

TIPS AND STRATEGIES

5 ways you can advocate for yourself

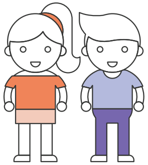
1. **Explain FCS simply.** Use clear, relatable language to help others understand your condition and its impact.
2. **Set food boundaries.** Kindly but firmly communicate your dietary restrictions and ask for support in meal planning and gatherings.
3. **Ask for emotional support.** Let loved ones know how they can help, whether by listening, learning, or offering encouragement.
4. **Correct misconceptions.** Gently address misunderstandings and promote better awareness.
5. **Lead by example.** Show consistency in managing your health, reinforcing the importance of your self-care needs.

Actor Portrayal. Not actual patients.

Teenagers

(around ages 13-17)

INDEPENDENT BUT HIGHLY SOCIAL



How they typically process information

- Have developed abstract thinking; can understand more complex medical explanations.
- Highly social; may feel self-conscious about differences between their family and others.
- Value independence but still need emotional support.
- Concerned about the future, including inheritance and life impact.

How to talk to them

- Be transparent; they can sense when information is withheld.
- Acknowledge social challenges, like explaining FCS to friends.
- Encourage autonomy in meal planning and advocacy.

Actor Portrayal.
Not actual patients.

Examples of how to talk about:

FCS and your nutritional needs

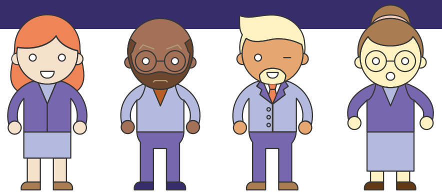
- *"FCS is a rare genetic condition that changed how my body processes fat. Most people's bodies break down fat, but mine doesn't. That means fat builds up in my blood if I eat it, so I have to be careful about what I eat so I don't have too much fat."*
- *"I work on managing my FCS by eating the right foods, so I can feel my best. With knowledge, support, and a healthy lifestyle, I can live a great life."*
- *"I don't want FCS to take over your life, but you're welcome to help with meal choices."*

Inheriting FCS

- *"FCS is genetic and only happens if both parents pass down certain genes. A genetic test may show if you have it."*
- *"If you do have it, we will face it together as a family."*

Social aspects of FCS

- *"It's okay to feel frustrated that our family eats differently from other families and that you have to explain FCS to people."*
- *"Our meals may look different than your friends' meals. You don't have to go into detail about why. 'My parent has a health condition, so we eat a little differently' is enough."*
- *"I don't expect you to eat exactly like me, but it helps when we plan meals together, so I feel included."*



4 common personality types

Your family and friends may fall into one of these groups, which can influence how you interact.

① Supportive Ally

Typical characteristics:

- Accepts and respects your needs
- Asks thoughtful questions and seeks info independently
- Offers support and respects boundaries; avoids pressuring you to “try a little”

How to talk to them: *Acknowledge and appreciate their efforts. Reinforce their understanding of FCS and be open to questions or collaboration.*

Example: *“You’ve been such a great support, and it helps so much. If you have any questions, let me know.”*

② Dismissive Skeptic

Typical characteristics:

- Won’t believe dietary restrictions are serious; downplays symptoms
- Questions medical advice and suggests alternative approaches
- Needs factual explanations
- Pressures you to eat unsafe foods

How to talk to them: *Requires firm boundaries and clear communication to ensure respect for health needs.*

Example: *“This isn’t about being picky or overreacting. It’s serious. FCS is a genetic condition where my body can’t remove fats, such as triglycerides (TGs) from the blood, so please don’t pressure me.”*

③ Unaware Misinterpreter

Typical characteristics:

- Wants to help but often forgets or misunderstands dietary restrictions
- Unintentionally offers unsafe foods; cannot fully grasp consequences

How to talk to them: *Benefits from clear, consistent reminders about FCS needs.*

Example: *“I’m just calling before I come over to dinner tomorrow to remind you that I can’t eat any fat, not even so-called ‘healthy fats,’ so I may bring my own food.”*

④ Overprotective Caretaker

Typical characteristics:

- Tries to manage your condition for you, sometimes to an overwhelming degree
- Shows excessive worry, leading to stress or guilt for you

How to talk to them: *Needs reassurance that support is appreciated but your independence is important.*

Example: *“I love that you’re looking out for me, but I sense that it may be causing you some stress. Just remember that I need to manage my FCS in a way that works for me.”*

4 ways to set boundaries

Protect your well-being by defining what behaviors you will and won’t accept.

① **Communicate your needs clearly.** Be firm but respectful. Clearly explain food restrictions and kindly decline unsafe meals. Use “I” statements to avoid blame, such as *“I need time to rest.”*

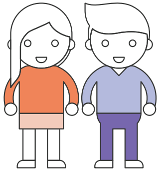
② **Say no without guilt.** Politely refuse requests that could compromise health. No explanation is needed beyond *“I can’t do that.”*

③ **Limit energy drains.** Protect your mental and emotional energy by recognizing when to step back and focus on your own well-being.

④ **Seek supportive environments.** Surround yourself with understanding people and consider seeking out others with FCS to talk to, possibly joining an FCS support community.

Adults

(around age 18+)



LOGICAL BUT POSSIBLY SKEPTICAL

How they typically process information

- May grasp complex medical information, but may also have strong beliefs about diet and health that shape their reactions.
- Base opinions on personal experiences and biases, such as *"I know people who eat healthy fats and are fine."*
- May be distracted by their own responsibilities and forget about yours.

How to talk to them

- Use clear, factual statements to dispel misconceptions.
- 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 and offer alternatives for food-based social gatherings.

Actor Portrayal.
Not actual patients.

Examples of how to talk about:

FCS and your nutritional needs

- *"FCS is a genetic condition where my body can't remove fats, such as triglycerides (TGs) from the blood. I have to eat a very low-fat diet or I can get very sick."*
- *"When my FCS flares up, I can feel extreme fatigue, severe stomach pain, or even end up in the hospital with pancreatitis. It's not just a little discomfort. It can be life-threatening."*
- *"There's no cure for FCS. Managing FCS means I have to be extremely careful with what I eat."*

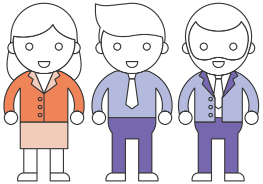
Addressing skepticism and pressure

- *"FCS isn't visible. Even when I look fine, my blood fat levels could be dangerously high."*
- *"I try not to make a big deal of it, but that doesn't mean it's not affecting me."*
- *"For me, no fat is healthy. My body can't process any type of fat properly, not even the so-called 'healthy fats.' What works for others doesn't work for me. They can build up and cause serious health problems like pancreatitis."*
- *"I appreciate your offer, but even a small bite can cause major problems for me. It's not like it is a preference. I'd love to have some. But it's 100% a medical necessity that I avoid it because it could send me to the emergency room."*

Reminders and social situations

- *"I know it's not something you may think about every day, so I just want to drop you a reminder to avoid any issues."*
- *"When we eat together, I might have to bring my own food or check restaurant menus carefully. I don't expect anyone to change what they eat, though."*
- *"What if instead of lunch, we meet up for a walk?"*

Spouses, partners, and significant others



EMOTIONALLY INVESTED AND DIRECTLY IMPACTED

How they typically process information

- Process FCS intellectually and emotionally, since it affects their shared lifestyle.
- May feel guilt, frustration, or helplessness more strongly than others in your life.
- May struggle with balancing support while maintaining their own lifestyle.

Actor Portrayal. Not actual patients.

How to talk to them

- Be open and vulnerable about FCS's emotional toll on relationships.
- Discuss practical concerns like meals, social life, and date nights.
- Involve them in medical discussions so they feel informed and included.
- Expect a range of reactions, from support to frustration.
- Reassure them that they can still enjoy foods and activities that you can't, without guilt.

Examples of how to talk about:

FCS's impact on the relationship

- *"FCS will shape our daily life, our meals, our decisions, and how we spend time together. But it doesn't have to define our future. We can still have a full and happy life."*
- *"You may want to fix things when I don't feel well, but just being here helps more than you realize."*
- *"I appreciate everything you do for me, but don't let FCS take over your life. Please take care of yourself, too."*

The emotional impact of FCS

- *"FCS affects you too. It's okay to have feelings about it and to talk about those feelings. You don't have to always be strong for me. We're in this together."*
- *"If you feel frustrated or helpless, know that your support means everything to me. I don't expect you to fix this."*

Nutrition

- *"Changing how we eat can feel overwhelming, but you don't have to give up everything you love or eat exactly like me."*
- *"It means a lot when we find meals we can both enjoy together."*
- *"FCS-friendly cooking can be tricky. Maybe we can learn some recipes together."*

NOTES

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

Know your TGs