

MANAGING LIFE WITH FCS

A Peer Support Toolbox Resource

On behalf of Arrowhead Pharmaceuticals and our FCS Lived Experience Council, a diverse group of individuals living with FCS, we have created this resource to share practical, actionable insights, tips, and tools for those affected by FCS. Informed by personal experience, these tools and resources are intended to support both individuals living with this ultra-rare condition and the caregivers who support them. We hope you find this collection helpful, relevant, and empowering.

Managing a diagnosis of Familial Chylomicronemia Syndrome (FCS) is challenging and can be isolating. Individuals living with FCS have expressed that connection to others going through something similar, having a sense of community and sharing with each other, and leaning on others for support has made such a difference in navigating everyday life.

This Peer Support Toolbox Resource is designed to provide easy-to-use information for the FCS community. This resource is not meant to provide medical advice. For medical questions and concerns, please contact a member of your healthcare team.

Living with FCS takes strength, courage, and community. Use this resource to help guide conversations, support your mental health, and live fully and socially while managing FCS.

"This resource is amazing! It incorporates all we have discussed as an FCS Lived Experience Council, our thoughts, concerns, and stories...every little piece of our hearts. If I had this to read when I was first diagnosed, it would have been an absolute game changer for me. It would have given me direction and resources, and hope. Real hope! This points people to resources where they can go from there. People need to own their own journey. It makes them stronger and strength is important. It makes them wiser and more informed—which is critical when you have a rare disease."

— Julie, living with FCS

The Peer Tips listed in this resource are compiled from our FCS Lived Experience Council. Recommendations for websites or apps are shared as personal tips, not endorsements.

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BUILDING YOUR SUPPORT NETWORK

You are not alone—others with FCS understand what you are going through and are willing to help. As you work to manage life with FCS, it's powerful and can be very helpful to leverage peer connections through established online communities and patient organizations like the FCS Foundation, Action FCS, The National Pancreas Foundation, Mission: Cure, and FH Europe Foundation.

Social connections to others who understand FCS and who have similar experiences are important to combat isolation and to build tools to help you manage life living with FCS. Peer support can help with both practical and emotional needs. Members of our FCS Lived Experience Council have shared how life-changing finding a sense of community has been for them as they manage their FCS and daily life.

Peer Tips

- Share your story; it can make you feel less alone and support and empower others.
- Participate in webinars and patient meetings for ongoing learning and connection.
- Recognize how much engagement and information is right for you, and when you may need to take a step back on online communities or chat boards to honor your limits (everyone is different and can be in different places in their journey).

Resources

- The following organizations can be a resource.
- LowerMyTGs.com: Stories, educational materials, and community connections.
- You can [Share Your High Triglycerides Story | Help Others](#).



FCS Foundation; livingwithfcs.org

Established in 2016 by two disease advocates directly impacted by FCS, the FCS Foundation connects the FCS community and provides resources and support for those with FCS. The Foundation hosts an annual Patient & Caregiver Meeting and works year-round to raise awareness and advocate for FCS. The Foundation operates as an all-volunteer organization alongside a medical advisory board of specialists working to advance future treatments.



Foundation of the NLA; learnyourlipids.com

The Foundation of the National Lipid Association is a non-profit focused on providing education and resources to help patients and their families manage and overcome lipid-related health problems that may put them at risk for a heart attack or stroke. They aim to translate scientific and medical progress into effective evidence-based guidance for optimal patient care. The Foundation's mission is to improve the welfare of patients and families affected by cholesterol and triglyceride problems. Their website provides resources for FCS patients and families.



The National Pancreas Foundation; pancreasfoundation.org

The mission of The National Pancreas Foundation (NPF) is to provide hope for those suffering from pancreatitis and pancreatic cancer through funding cutting edge research, advocating for new and better therapies, and providing support and education for patients, caregivers, and health care professionals. The NPF helps those living with FCS navigate the challenges of this often misunderstood disorder by providing patient and provider resources on FCS and pancreatitis, raising awareness, and building connection through events. By amplifying the voices of those affected by FCS, the NPF helps ensure the needs of this community are recognized and addressed, ultimately improving quality of life and outcomes for patients.

Mission:Cure

Mission Cure; missioncure.org

Mission:Cure is a pioneering non-profit dedicated to transforming the lives of those affected by pancreatitis through a strategic, patient-centered approach aimed at finding effective treatments and ultimately a cure. Mission:Cure will continue to expand its support for the FCS, MCS, and severe hypertriglyceridemia communities by delivering educational resources through webinars, web pages, blog posts, and stories to help patients navigate their disease and management while fostering hope and empowerment. Through strategic collaborations and relentless advocacy, Mission:Cure drives meaningful change, ensuring pancreatitis patients receive the care, support, and hope they deserve.



Familial
Chylomicronaemia
Syndrome

Action FCS; actionfcs.org

Founded in 2015 by a patient, Action FCS is a U.K. charity to raise awareness and educate about FCS, running an annual FCS Awareness Day on the first Friday of November, and running education events for the community both alone and with other organizations. They have resources to help manage the condition and a supportive community for people affected by FCS. The organization advocates for excellent care and has represented patients in medicines regulatory processes, and works with their medical advisory group and other specialists to improve care.



**FH Europe
Foundation**

FH Europe Foundation; fheurope.org

The Foundation's (FHEF) mission is to enhance awareness, understanding, and access to diagnosis and treatment for inherited lipid conditions—including FCS among others—across Europe and beyond. By doing so, the Foundation ensures that those affected receive optimal care and support, leading to longer, healthier lives. In addition to its European efforts, FHEF is progressively extending its reach to global communities through a series of international initiatives like the FCS WhatsApp Group and fostering global collaboration through the Patient Ambassador Program, international patient support groups, and advocacy efforts like the recent call for a World Health Assembly (WHA) Resolution on Rare Diseases. By acting as a convener for the international community, FHEF drives meaningful progress in addressing familial hyperlipidemia on a global scale.

**There are also two online, closed and curated
Facebook communities for those with FCS**

U.S.: [FCS Facebook Support Group](#)

U.K.: [FCS Facebook Community](#)

UNDERSTANDING FCS

Because FCS is an ultra-rare condition, it can be difficult to find helpful, relevant information. This is complicated because the impacts of FCS can be highly variable depending on when and how you were diagnosed, your progression, and how the condition manifests itself physically and in your daily life. Individuals living with this condition are like “FCS snowflakes – each unique in how FCS impacts their health.”

Peer Tips

- Knowledge is power. Become an expert in your FCS. You need to understand what works for you in terms of food, fat intake, and best approaches for minimizing pancreatitis.
- Connection to the community is important for information and support, but keep in mind the variability of FCS as you engage with others whose experiences may be different from yours.
- Adapt recommendations made by others to your unique situation, based on how you are feeling.
- Lean on your healthcare team to discuss any medical recommendations or advice.
- Develop an understanding of the genetic aspects of your FCS to help you and your family understand their risks.
- Consider sharing your experience, story, and expertise to help others better understand FCS.

Tools & Resources

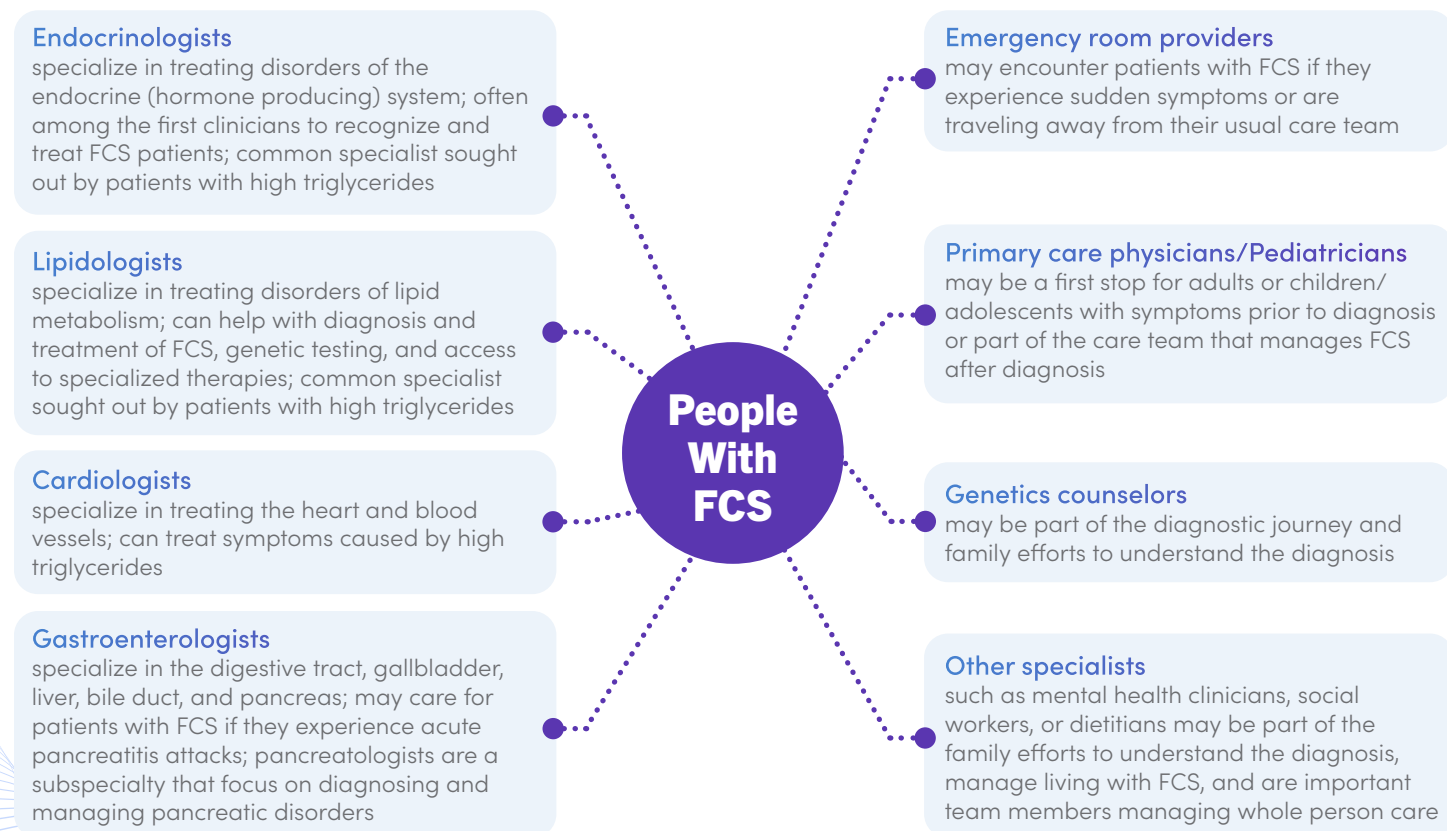
- The organizations and online communities listed above.
- [LowerMyTGS.com](https://www.lowermytgs.com/): Stories, educational materials, and community connections.
- Other rare disorder patient organizations, such as National Organization for Rare Disorders (NORD), which advances practical, meaningful, and enduring change so people with rare diseases can live their fullest and best lives. Every day, they elevate care, advance research, and drive policy in a purposeful and holistic manner to lift up the rare disease community.
- [Spotlight on FCS](#) voice of the patient paper. Sharing the lived experiences of 14 individuals from the FCS community, transforming their personal journeys into a powerful catalyst for systemic change in FCS awareness, diagnosis, and care. Paper highlights include:
 - Real-life experiences of those living with FCS
 - Ways to support newly diagnosed individuals and families
 - Challenges in diagnosis and ongoing care
 - Critical unmet needs in the FCS journey
 - Suggested actions to help drive systemic change

NAVIGATING MEDICAL INTERACTIONS & COMMUNICATING WITH HEALTHCARE PROVIDERS

Living with FCS might entail a significant number of interactions with medical professionals, from pre-diagnosis through diagnosis, management, pancreatitis flares, and related medical issues. Communicating symptoms and impacts of FCS with various medical professionals can be challenging and so can navigating the hospital and talking to medical professionals when you have pancreatitis. Most healthcare providers do not understand FCS and its complexity, leading to frequent misunderstandings and stigma in the emergency room and hospital settings. It can be challenging to build a care team that best meets your situation, finding the right specialists and ensuring they are addressing all your needs.

Peer Tips

- **Become a Lay Expert:** Learn as much as you can about FCS to explain it clearly to new providers. Let your care team know that you are an expert when it comes to your FCS. Understand that you have rights as a patient when you are in a healthcare setting, and you should feel empowered to ask for what you need.
- **Build a Multi-Disciplinary Care Team:** Find professionals who are ready to listen to you and engage in a shared approach with you in managing your care in a personalized way. Your care team should include a variety of specialists who can manage all aspects of your FCS. This often will include a primary care physician, endocrinologist and/or lipidologist, pharmacist, social worker/therapist (mental health professional), dietician, and FCS peers.



- **Ask questions:** Ensure you feel comfortable with members of your care team.
- **Minimize Administrative Complexity:** Where possible, try to keep members of your team in the same healthcare network or system to minimize paperwork, communications challenges, and insurance complications.
- **Prepare an “FCS Folder”:**
 - A [letter from your specialist](#) outlining your diagnosis, treatment protocol, and pain management needs.
 - **Spotlight on FCS** white paper to share with unfamiliar providers.
 - QR codes linking to reputable resources (e.g., [LowerMyTGs.com](#), and patient organizations listed above).
- **Advocate Confidently:**
 - Ask for specifics about the people who are treating you (e.g., what is their specialty and what experience do they have with FCS, etc.) Ask your care team to clarify any test results and provide explanations about treatment/management decisions you are being asked to make.
 - Request to speak to a **charge nurse or patient advocate** if not being heard.
 - Don’t hesitate to involve family members for support during hospital visits.

Tools & Resources

- The National Pancreas Foundation [“Questions to Ask Your Doctor”](#) checklist.
- Foundation of the National Lipid Association’s (NLA) [Lipid Specialist Finder](#) for locating lipid specialists who understand FCS.
- [Template ER Letter](#) for FCS patients (customizable with your doctor).
- [Spotlight on FCS](#) white paper.

MANAGING MENTAL HEALTH & STRESS

FCS affects nearly every aspect of life—impacting not only a person’s physical health, but also relationships, family life, and ability to work or engage socially. Unsurprisingly, patients and loved ones often face significant mental health challenges alongside the condition’s physical burden. Importantly, we’ve also heard anecdotally from Council members that emotional and physical stress can potentially affect triglyceride levels. Managing mental health and stress is an important part of your full care plan. For those who have been living with FCS for many years, as well as caregivers, prioritizing mental health is just as essential as managing the physical aspects of FCS.

Peer Tips

- **Acknowledge Emotions:** A diagnosis can bring grief and frustration. It can also create anxiety in a variety of ways, from stress in trying to avoid pancreatitis flares, meal planning pressures, impact on caregivers, and concerns about family genetic risk for children. Give yourself grace.
- **Create Your Own Space for Calm:**
 - Step away during stressful moments.
 - Use breathing or mindful exercises or digital apps. One of our FCS Lived Experience Council members likes **Calm**.
 - Meditation can be a great way to take a break and re-center.
- **Seek Support:**
 - Finding useful information and appropriate support can be challenging. Keep in mind that sometimes the best thing to do is take a break from social media and other platforms if you feel overwhelmed.
 - Find peer support through patient organizations. Your family and spouse can be a wonderful support, although it is beneficial to connect with others who are walking similar steps without judgment.
 - Engage with therapists, counselors, or faith leaders.
 - Find a dietician who has experience with lipid conditions who can help with meal planning ideas. If you see a lipid doctor or have a lipid center nearby, it might be helpful to ask them for a referral to a dietitian that understands lipid conditions. If your dietician is less familiar with the complexities of an FCS diet, they may inadvertently increase your chances of a pancreatitis flare by suggesting a traditional low-fat diet.
- **Practice Self-Kindness:**
 - Do not be hard on yourself or overly judgmental. It is OK to seek and need support, especially when you are having a pancreatitis flare, are experiencing challenging symptoms, or finding it hard to manage the restrictions and modifications needed to best manage your FCS.
 - Rest when you need it—overexertion can lead to pancreatitis flares.

- Break tasks into smaller parts or delegate.
- **Avoid Isolation:** Find one trusted person who understands or another FCS patient to mentor you or lean on.

Tools & Resources

- **Mental Health Tools:** Search for calm-inducing digital apps or journaling tools.
- **Therapy Finder:** Use local or telehealth directories for licensed mental health professionals.
- **Finding professional help:** Search online resources or therapy finders to determine what is right for you.

How to Handle Anxieties That Can Arise from FCS Being a Genetic Condition

Finding out that your FCS condition is related to your genetics can bring with it a variety of anxieties, including the concern about whether your children may also have FCS. Once you have a genetic test report confirming FCS, you may be seeking information about the potential risks to your family members and what this means for you.

Peer Tips

- **Seek Information and Support:** Leverage the FCS Facebook group network and engage with FCS advocacy organizations to learn from others' experiences. There are also other organizations that support and provide umbrella representation for rare disease communities. You may find connecting with them to be helpful as you seek and use available resources about rare genetic conditions.
- **Meet with a Genetic Counselor:** Consider ask your healthcare provider for a referral to a counselor who can help you understand your genetic testing report.
- **Find a Therapist that is Right for You:** It is always good to have someone to talk to about the anxieties that arise in dealing with a condition like FCS.

Tools & Resources

- Search online for genetic counselors or additional resources that might be helpful, or speak to your doctor or hospital system for a referral.

LIVING SOCIALLY WITH FCS

Living socially with FCS can be challenging considering the restrictions that it creates. It has been shared by people in the FCS community that they tend to think about what they eat and how to avoid pancreatitis all the time. This makes it extremely challenging and stressful to engage socially with others who do not have FCS and who may not be familiar with the severe limitations it imposes. Dining out, going to social gatherings and celebrations, and travel require advance planning and can cause anxiety for you and loved ones. These situations may lead to feelings of isolation.

Peer Tips

- **Plan Ahead:**

- Review menus online before going out.
- Call restaurants to ask about ingredients.

- **Communicate Clearly:**

- Ask for “no butter” or specific substitutions.
- Ask how items are prepared.
- One of our Council members found that describing their condition as an “allergy to fat” in certain settings helps communicate the seriousness of their low-fat dietary requirements to restaurant staff.
- It is becoming very common for restaurants to ask if there are special dietary restrictions. Recognize that no-fat can be viewed as similar to the many types of special diets that people rely on (such as gluten free, dairy free, specific allergen-free).

- **Bring Your Own Food:**

- Join the “Do Not Care Club” mindset—your health comes first!
- Pack a small cooler or snacks for travel or social events.
- Take seasonings and FCS-friendly sauces and dressings with you to add flavors.

- **Check Ingredients:**

- Verify labels and packaging, even if a product is labeled “fat-free.”
- One of our Council members suggested to trust your taste buds. If it tastes like there are ingredients you can’t have in the food item, give yourself the room and permission to check with kitchen staff to confirm ingredients. No one can advocate for you better than you!

- **Track Your Intake:**

- Consider using digital apps or tools to log your meals and track nutrition so you can better stay within your fat limits or other nutritional needs.

- **Find Supportive Spaces:**

- Identify restaurants or chefs who accommodate your needs.
- Build relationships with regular establishments for stress-free dining where you can establish an ongoing relationship with staff who know your situation and can easily accommodate.

Tools & Resources

- **Meal or nutrition tracking** digital apps
- **Safe Recipe Adaptation Guide:** Modify comfort foods with FCS-friendly ingredients.
- **Travel Planning Templates:** Create checklists for trips and dining with FCS.
- **[Foundation of National Lipid Association's Low-Fat Cookbook](#)**

Scan the QR code to view OnDemand peer support videos and additional informational FCS resources.

