

LIVING WITH Familial Chylomicronemia Syndrome (FCS)



What FCS Does to Your Body

When you have FCS, the enzyme that breaks down triglycerides from the diet is absent or does not work well, causing triglyceride levels in the blood to build up. You are unable to remove these fats from your blood and you must avoid eating foods high in fat.

A buildup of triglycerides in the blood can cause severe abdominal pain due to pancreatitis (inflammation of the pancreas). Rarely pancreatitis can be fatal. Sticking to a low-to-no-fat diet is essential to reduce the pain and pancreatitis risk.



I Have FCS and I Need to Change My Diet – What’s Next?

Helpful Tips:

- ◆ Limit fat to 10-15% of total calories (no more than 20 grams/day for a 2000 calorie diet).
- ◆ Limit carbohydrates and when choosing carbohydrates, choose those with fiber. Too many refined, simple carbohydrates can increase triglycerides so it is important to avoid them as much as possible.
- ◆ Use Medium Chain Triglyceride (MCT) oil, if needed, to meet calorie needs by adding it to foods or using it to cook with. It is used to provide extra calories and has not been shown to increase blood sugar or triglycerides. *See below for more information on MCT oil.*
- ◆ Utilize a food diary or track your food intake using a mobile app.
- ◆ Seek the help of a registered dietitian nutritionist (RDN) for advice on how to manage and plan your meals and assure your nutritional needs are met.

WHAT TO AVOID

- ◆ Fat-containing foods
(fatty meats, oils, fried foods)
- ◆ Refined Starches
- ◆ Sugars and concentrated sweets
- ◆ Sugary drinks, including 100% fruit juice
- ◆ Alcohol

WHAT TO EAT

- ◆ Vegetables
(half your plate should be vegetables)
- ◆ Lean proteins
- ◆ Whole grains and legumes (beans)
- ◆ Fat-free dairy products



Using MCT Oil

- ◆ Purchase pharmacy grade or purified MCT oil. Do not confuse MCT oil with “coconut” oil, which contains both long and medium chain fatty acids. Pure MCT oil should only contain Caprylic Acid and Capric Acid. You can find MCT oil online or in specialty stores and pharmacies.
- ◆ Start slowly by taking one measured tablespoon of MCT oil at one meal daily (some individuals start with even less). It can be added to a shake/smoothie or mixed with vinegar to make a salad dressing. You can use it to sauté foods, but use very low heat, as MCT oil has a low smoke point and burns easily.
- ◆ If you do not have any gastrointestinal side effects after a couple of days, add another tablespoon to another meal. Repeat after several more days to a maximum intake of 3-4 tablespoons divided during the day with food. MCT oil is best tolerated with food.

