FCS Caregiver Toolkit

Symptom Trackers

Tracking symptoms helps spot patterns, prevent crises, and give clinicians clear, actionable information.

Daily Symptom Log (quick check-in)

Use daily or as needed.

Date: ________________

Energy level: ☐ High ☐ Moderate ☐ Low

Abdominal pain: ☐ None ☐ Mild ☐ Moderate ☐ Severe

Location: ____________________________________

Duration: ____________________________________

Nausea/vomiting: ☐ No ☐ Yes (details)

Bloating/fullness: ☐ No ☐ Yes

Appetite changes: ☐ No ☐ Yes

Bowel changes: ☐ No ☐ Yes

Fever: ☐ No ☐ Yes (temp): _______

Missed school/work? ☐ No ☐ Yes

Caregiver Tips

- Set phone alarms or use a shared digital calendar.
- Keep a printed version on the fridge or in a care binder.
- Track **missed doses** and **side effects** to share with clinicians.
- Bring all medications (or a list) to appointments.

Trigger & Pattern Tracker

Helpful for identifying food, stress, or illness-related triggers.

Meals/snacks (fat content noted): __________________

Illness/infection present?: __________________

Stress or emotional events: __________________

Physical activity: __________________

Symptoms afterward (and timing): __________________

Red Flag Tracker (urgent)

Document and seek medical guidance if these appear:

- ☐ Severe or persistent abdominal pain
- ☐ Repeated vomiting
- ☐ Signs of pancreatitis
- ☐ Dehydration
- ☐ Rapid symptom worsening

Medication Schedules

Consistency and clarity matter—especially when multiple caregivers are involved.

Date/Time	Medication	Dose	With Food?	Purpose	Side Effects

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Appointment Notes & Care Team Prep

Appointments are short—this helps you get the most out of them.

Before the Appointment

Bring or summarize:

- Recent symptom patterns
- Food tolerance challenges
- Medication effects or side effects
- ER visits or missed school/work
- Emotional or behavioral changes

Key Questions to Ask Clinicians

- Are current symptoms typical for FCS or a warning sign?
- Any adjustments needed to diet, medications, or supplements?
- What symptoms should trigger urgent care?
- How do illness, growth, or stress affect FCS?
- Are there new therapies, trials, or support resources?
- What should schools/daycare know?

Notes During the Visit

- Provider recommendations:
- Changes to treatment plan:
- Follow-up tests or labs:

Next appointment date: ______________________________

Communicating With "Your Village"

You don't have to do this alone. Clear communication reduces misunderstandings and builds support.

Explaining FCS to Family & Friends (Adults)

Simple script:

"FCS is a rare genetic condition that makes it hard to process fat. Even small amounts can cause serious pain or illness, so diet and routines are critical. Support and understanding really help."

Tips

- Be specific about what helps (meal planning, flexibility, empathy).
- Correct myths gently ("It's not a preference diet—it's medical").
- Share trusted educational resources if helpful.

Talking to Children About FCS

Young children

- Use simple, concrete language:
  "Some foods make my/your body hurt, so we eat special foods to stay healthy."
- Reassure them it's not their fault and not contagious.

Older children/teens

- Encourage questions and honesty.
- Acknowledge frustration and unfairness.
- Give them age-appropriate responsibility without making them the "food police."

Schools, Daycare & Care Settings

What to share

- Clear list of safe vs. unsafe foods
- Emergency symptoms and action plan
- Importance of not sharing food
- How stress or illness may affect the child

Helpful tools

- Written care plan or 504/IEP (if applicable)
- Pre-approved snacks
- One point of contact at school

Supporting Emotional Health

FCS affects more than the body—it can weigh heavily on mental and emotional well-being.

For the Patient

- Validate feelings: anger, sadness, isolation are normal.
- Encourage expression through talking, art, or journaling.
- Help them connect with peers or patient communities.
- Celebrate non-food milestones and joys.

For Caregivers

- Acknowledge burnout—it's common and real.
- Accept help when offered (meals, rides, childcare).
- Schedule breaks, even small ones.
- Consider counseling or caregiver support groups.

As a Family

- Keep conversations open and judgment-free.
- Separate the disease from the person ("FCS is hard" vs. "you are difficult").
- Focus on what can be controlled, not perfection.

Caregiver Quick-Reference Checklist

☐ Symptom log updated
☐ Medications given and tracked
☐ Safe food available
☐ Emergency plan accessible
☐ School/daycare informed
☐ Emotional check-in done

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