COMMUNITY LIVER ALLIANCE ™
GLOBAL AWARENESS. LOCAL IMPACT.

LIVING WITH A RARE LIVER DISEASE

Practical tools to understand your care plan, prepare for visits, track changes, and participate in decisions.

A rare liver disease diagnosis can bring relief at finally having an explanation — and a new set of questions. Rare liver diseases differ in their causes, symptoms, treatments, progression, and monitoring. This toolkit focuses on the practical skills that can help across diagnoses: understanding your care plan, preparing for visits, tracking changes, communicating with your care team, finding support, and participating in decisions.

Name _____ **Date** _____

Community Liver Alliance

This guide is educational and does not replace individualized medical advice. Talk with your healthcare team about your specific situation. In an emergency, call 911.

START HERE

You do not need to learn everything at once. Ask your care team: "What are the three most important things you want me to understand about my diagnosis right now?"

Their answer

1. Understanding Your Diagnosis

1. What is the exact name of my condition?

2. What part or function of my liver does it affect?

3. How will we monitor it?

4. What symptoms or changes should I report?

5. Who should I contact when I have questions?

My Diagnosis Snapshot	Notes
Exact diagnosis	
Date diagnosed	
Liver specialist	
Other specialists	
Current medicines/supplements	
Allergies	
Next appointment	
Next labs/tests	
Best contact for questions	

2. Building Your Care Team

Depending on the condition, your team may include a hepatologist, gastroenterologist, primary care clinician, advanced practice provider, pharmacist, dietitian, behavioral health professional, genetic counselor, transplant team, or other specialists.

Team Member	Why I See Them	Contact / Next Visit
Liver specialist		
Primary care		
Other specialist		
Pharmacist		
Other		

ONE IMPORTANT QUESTION

“Who is coordinating my overall care?”

3. Preparing for a Specialist Visit

Before the visit, consider bringing:

- ☐ An updated medication and supplement list
- ☐ Relevant test results, if your team asks you to bring them
- ☐ Your top three questions
- ☐ Recent symptom notes or changes
- ☐ Insurance/pharmacy information
- ☐ A caregiver or support person, if helpful

My Top Three Questions	Notes
1.	
2.	
3.	

Before I leave, I understand:

- ☐ What happens next
- ☐ Medication instructions
- ☐ Symptoms or changes I should report
- ☐ Who to contact with questions
- ☐ Whether anything changed
- ☐ Tests I need
- ☐ When I return

4. Understanding Monitoring, Tests, and Results

Monitoring varies by diagnosis. Instead of memorizing every test, focus on understanding why a test is being ordered and what your team is watching over time.

1. What are we measuring?

2. Why does it matter for my condition?

3. Are we looking at one result or a trend over time?

4. What might cause this result to change?

5. Could this result change my care plan?

Tests you may hear about can include liver blood tests, imaging, fibrosis assessment, disease-specific laboratory tests, genetic testing, and biopsy. Not every test is appropriate for every rare liver disease.

5. Symptom & Change Tracker

Track not only whether a symptom is present, but also how it affects your day and whether it is different from your usual baseline.

Symptom / Change	0–10	When / Pattern	Impact on My Day	What I Want to Ask
Fatigue				
Itching				
Pain/discomfort				
Sleep				
Appetite				
Mood				
Other				

A USEFUL PHRASE FOR YOUR VISIT

“This is different from my normal because...”

6. Treatment Conversations

1. What is the goal of this treatment?

2. How will we know whether it is working?

3. What side effects or changes should I watch for?

4. What should I report right away?

5. How long might I take it?

6. Could it interact with my other medicines or supplements?

7. What happens if this treatment does not work for me?

8. Are there other options we should discuss?

9. Will insurance authorization or specialty pharmacy steps be involved?

7. Caregiver Corner

Caregivers may help organize information, attend appointments, notice changes, manage practical tasks, and provide emotional support. Caregivers also need information, boundaries, and support of their own.

- Ask the patient what kind of help they want.
- Keep a shared list of questions and next steps when appropriate.
- Avoid assuming that looking well means feeling well.
- Pay attention to your own stress, sleep, and support needs.
- Ask the care team what warning signs or changes you should know about.

CONVERSATION STARTER

“What would be most helpful right now — listening, helping solve something, or taking something off your plate?”

8. Financial & Practical Navigation

Topic	Need help? ☐	Contact / Resource / Notes
Insurance and prior authorization questions	☐	
Medication assistance and specialty pharmacy navigation	☐	
Workplace or school accommodations	☐	
Disability and leave resources	☐	
Transportation and lodging resources when applicable	☐	
Caregiver support resources	☐	
Disease-specific nonprofit and peer-support organizations	☐	
Community Liver Alliance education and support resources	☐	

9. Research & Clinical Trials

Research participation is voluntary. A clinical trial may or may not be appropriate for you. Ask what the study is testing, what participation involves, what risks and possible benefits are known, what costs are covered, how much travel or time is required, and whether participation changes your usual care.

1. What is the purpose of this study?

2. Why might I be eligible?

3. What would I need to do?

4. What are the known risks and possible benefits?

5. Which costs are covered and which are not?

6. Who do I contact with questions?

7. Can I leave the study if I change my mind?

10. My Rare Liver Disease Action Plan

What I Know	What I'm Watching	What I'm Asking	What Happens Next

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