Alpha-1 Antitrypsin Deficiency Liver Disease

DISCUSSION GUIDE

Talking With Your Healthcare Professional

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This guide is not intended to provide medical advice and/or replace consultation with a health care provider.
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SECTION 1:
UNDERSTANDING ALPHA-1 ANTITRYPSIN DEFICIENCY

What is Alpha-1?

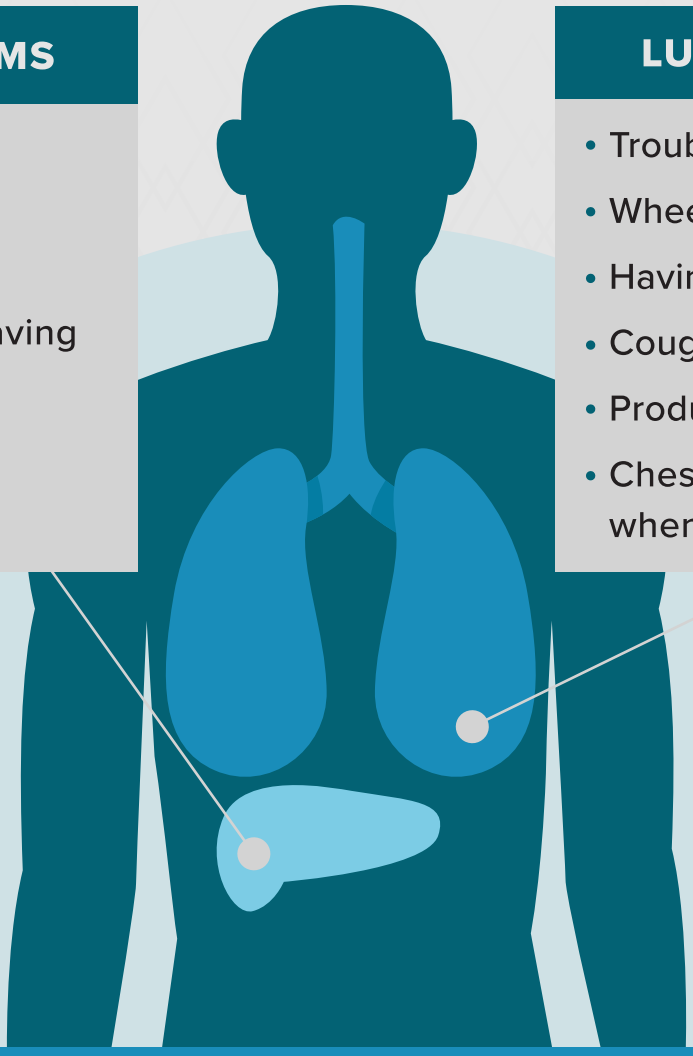
The liver produces a protein called alpha-1 antitrypsin. This protein travels in the blood and helps protect the lungs. If there are problems making or moving this protein, it can cause Alpha-1 antitrypsin deficiency (Alpha-1).

Alpha-1 is a genetic condition. This means if one person in a family has it, other family members might have it too. Alpha-1 can cause liver and/or lung problems called Alpha-1 liver disease and/or Alpha-1 lung disease.

Alpha-1 Symptoms* May Include:

LIVER SYMPTOMS

- Yellow skin or eyes (jaundice)
- Swelling stomach
- Vomiting blood or having blood in your stool
- Fatigue
- Weakness



LUNG SYMPTOMS

- Trouble breathing
- Wheezing
- Having allergies all year
- Coughing a lot
- Producing a lot of mucus
- Chest pain that gets worse when you breathe in

*This is not intended to be an exhaustive list. Individual experiences may vary.

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Why and How to Get Tested for Alpha-1

A healthcare professional may want to test you for Alpha-1 if you have any of these:

1. A family member who has been diagnosed with Alpha-1 liver disease or Alpha-1 lung disease
2. Liver disease without a known cause
3. Lung disease with no known health risks (smoking, air pollution, etc.)
4. Long-lasting asthma, bronchitis, or allergies all year
5. A skin condition called necrotizing panniculitis (painful, raised spots that form sores)

The first step to a possible diagnosis is talking with your healthcare professional.

Your doctor might order a **simple blood test** that can be done at their office. The test checks the level of alpha-1 antitrypsin protein in your body. If the level is lower than normal, your healthcare professional might suggest **genetic testing**. This means there might be a cheek swab or another blood test to see if you have the gene change that increases the risk of liver or lung disease.

If your healthcare professional thinks Alpha-1 is affecting your lungs or liver, they may also do **lung function tests**, take **X-rays** or **CT scans** of your lungs, or do an **ultrasound** or **biopsy** of your liver.

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SECTION 2:
MANAGING YOUR MEDICAL APPOINTMENTS

You've been diagnosed with Alpha-1 liver disease. How can you manage your medical appointments going forward?

How and When to Involve Your Medical Team

Working with your medical team is important to stay healthy when managing Alpha-1 liver disease. Regularly talking to your healthcare professionals will help you in receiving the right treatment, support, and/or tests to find the best plan for you.

Building Your Medical Team

Scheduling and going to **medical appointments** are important to managing your Alpha-1 liver disease. It gives you time to talk to your medical team and make good decisions about your health.

It is important to have a medical team with **different specialties** to meet your specific needs. Ask your primary care physician (PCP) to refer you to specialists, like lung, liver, or other healthcare professionals.

If possible, try to have your medical team all in the **same hospital**. This will make it easier for them to talk to each other and keep track of your care.

In this section, you will find helpful tips and questions to bring to your appointments so you will leave with a clear understanding of your healthcare plan.

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Getting Ready For Your Appointments

Preparation is Important

Before your appointment, write down any changes in your symptoms and health. Since your time with your healthcare professional may be short, use the questions below to help you prepare so you don't forget anything important.

Be Honest

It is important to share your symptoms, worries, and changes in your health with your medical team. This information is important to your medical team.

Ask Questions

If you do not understand something, ask your healthcare professional to explain it in simpler words. Make sure you leave the appointment understanding your condition, treatment plan, and any lifestyle changes you should make.

Know Your Family's History

Bring information about your family's health, like any medical conditions they have and the age they were diagnosed.

Know Your Medications

Bring a list of all the medicines you're taking and any side effects you have had.

Take Notes

Bring a notebook to write down what your healthcare professional says, their advice, and next steps.

Bring Support

Consider bringing an informed and trusted friend or family member to help support you, take notes, and ask questions.

NOTES

Examples of information that is important to share with your medical team:

"For the past few weeks, I have been feeling extremely tired and weak."

"My mom and brother both have liver disease."

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QUESTIONS YOU SHOULD BE ASKING

Your treatment options may be different depending on the type and seriousness of your disease and the symptoms you have. You can work with your healthcare professionals, including lung, liver, and other specialists, to find the treatment plan that works best for you. **Here are some questions to help guide your conversations:**

BEGINNING OF YOUR JOURNEY

Testing

- Do any of my family members need to get tested?

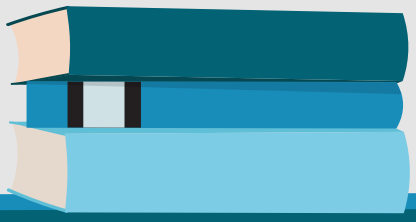
Understanding and Monitoring Your Alpha-1 Liver Disease Symptoms

- Should I see a specialist, like a lung, liver, and/or other healthcare professional?

- How often should I visit my primary care doctor?
- How often should I visit my specialists?
- Who should I call if I am worried about my symptoms?

- How will my disease be monitored?
- Can you help me understand the key symptoms of Alpha-1 liver disease? What symptoms should I watch for with my liver?

- Are there any resources where I can learn more about Alpha-1 liver disease and how to manage it?



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NAVIGATING YOUR JOURNEY

Lifestyle Changes

- What can I do to stay as healthy as possible and reduce the impact of Alpha-1 liver disease on my life?

- How will Alpha-1 liver disease impact my social life?
- Are there any special precautions I should take?
- Are there any foods or medications I should avoid?

Mental and Emotional Health

- If I feel overwhelmed, what can I do to feel better emotionally?
- Are there behaviors or symptoms my family or friends should watch for?

Disease Management

- What medications or treatments might be right for me?
- Are there any clinical trials I should know about?

LOOKING AHEAD

Additional Support

- What foundations, patient organizations, or community groups can I go to for support?

Staying informed and prepared is important for managing your Alpha-1 liver disease. **You are not alone.** Your medical team, family, friends, caregivers, and patient organizations are all here to support you.

Check references on page 8 to find more support resources for Alpha-1 liver disease.

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SECTION 3:
NOTES & REFERENCES

Please use the space below to write down your questions, thoughts, and feelings. Use these notes during your medical appointments.

Living with an Alpha-1 liver disease diagnosis can be difficult, but you can find support and information through patient support organizations.

Alpha 1 Deutschland e.V.

ALPHA-1 FOUNDATION

Alpha 1 UK

AlphaNet Canada

GLOBAL ALLERGY & AIRWAYS PATIENT PLATFORM

GLI GLOBAL LIVER INSTITUTE

Liver Patients International

TRIO®

alpha1-deutschland.org • alpha1.org • alpha1.org.uk • alphanetcanada.ca
gaapp.org • globalliver.org • liverpatientsinternational.org • trioweb.org

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