

If you have been diagnosed with Alpha-1 Antitrypsin Deficiency (AATD, Alpha-1), it may be helpful to discuss the topics below with your AlphaNet Coordinator and your healthcare provider. More information about these topics is provided in AlphaNet’s Big Fat Reference Guide (BFRG) (<https://bfrg.alphanet.org/>).

Alpha-1 Antitrypsin Deficiency Diagnosis

- ✓ My genotype/phenotype is: _____ Examples include ZZ, MZ, MS, and many others.
- ✓ My Alpha-1 serum level at diagnosis was: _____ mg/dl.
- ✓ Save the original document with the information about your genotype/phenotype and Alpha-1 level.
- ✓ Ask about evaluation by a healthcare provider with expertise in Alpha-1 (lung and/or liver disease).
- ✓ Consider testing other family members. Discuss this with your healthcare provider.

Lung Diagnosis and Relevant Symptoms

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| <ul style="list-style-type: none"> ✓ I have been diagnosed with one or more of the following lung conditions. <ul style="list-style-type: none"> <input type="checkbox"/> Emphysema. <input type="checkbox"/> Chronic bronchitis. <input type="checkbox"/> Chronic obstructive pulmonary disease (COPD). <input type="checkbox"/> Bronchiectasis. <input type="checkbox"/> Asthma. <input type="checkbox"/> Other lung disease: _____. | <ul style="list-style-type: none"> ✓ If you experience any of the following symptoms, discuss them with your healthcare provider. <ul style="list-style-type: none"> <input type="checkbox"/> Heartburn. <input type="checkbox"/> Sinus problems (such as sore throat or drip/drainage). <input type="checkbox"/> Sleep problems (such as snoring or being tired when you wake up). <input type="checkbox"/> Skin problems (such as rash, itching, or pain). <input type="checkbox"/> Liver symptoms (such as bleeding, fatigue, or yellow skin). |
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Testing

- ✓ The following testing is recommended:
 - Pulmonary function testing annually.
 - Chest x-ray or chest CT (baseline and as indicated).
 - Bone densitometry (baseline and as indicated).
 - Liver ultrasound after age 50 and as indicated.
 - Liver blood panel annually.

Medications

- ✓ Keep a complete written list of all your medications.
- ✓ Some individuals with lung disease due to AATD are prescribed augmentation therapy. If you are prescribed augmentation therapy you should note the brand name _____, dosage _____, and frequency of infusion _____.
- ✓ If there are issues with my augmentation infusion supplies, I call _____.
- ✓ Some individuals with lung disease due to AATD need supplemental oxygen. This may be prescribed only when sleeping or when physically active, or supplemental oxygen may be needed throughout the day and night.

Immunizations, Diet, and Nutrition

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| <ul style="list-style-type: none"> ✓ The following immunizations can help you stay healthy: <ul style="list-style-type: none"> <input type="checkbox"/> Influenza vaccine <input type="checkbox"/> Pneumococcal (<i>Pneumonia</i>) vaccine <input type="checkbox"/> TDaP (<i>Tetanus, Diphtheria, Whooping Cough</i>) vaccine <input type="checkbox"/> Hepatitis A vaccine <input type="checkbox"/> Hepatitis B vaccine <input type="checkbox"/> COVID vaccine | <ul style="list-style-type: none"> ✓ My current weight is: _____ ✓ I am: <ul style="list-style-type: none"> <input type="checkbox"/> Underweight <input type="checkbox"/> At a healthy weight <input type="checkbox"/> Overweight ✓ Discuss the use of vitamins and mineral supplements with your healthcare provider. ✓ Develop a weight management plan and an exercise routine. |
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