



 AlphaNet

 AlphaNet

Individual Health Management Plan

A long-term guide for
Alphas with Liver Disease

Skinny Little Reference Guide™

This is a guide to help build a collaborative plan between you and your healthcare provider. The goal of a health management plan is to look beyond the next scheduled healthcare provider visit and develop a plan to maintain health and evaluate for changes with a view that spans months or years into the future. It is recommended that this collaborative health management plan be reviewed with your healthcare provider on an annual basis.

The column on the right, “My Personal Guide to Alpha-1 Treatment for Liver Disease” has been prepared to help you navigate the details of dealing with an Alpha-1 diagnosis. It includes places for you to record essential information, discussion topics to talk about with your doctor and/or nurse and direction about tests, issues and lifestyle decisions.

On the left, you have a guide for your doctor and/or nurse to follow. Plan to meet on at least an annual basis and review this information. Be sure to take along this handy reference and share it with those who are providing your medical care. It is also a good idea to keep a list of any additional questions, as well as a list of all your medications, tucked into this brochure so you will have it on-hand.

If your doctor and/or nurse would like their own copy of the “Healthcare Provider Treatment Plan for Alphas with Liver Disease” they can access the information by visiting the AlphaNet website at www.alphanet.org, and printing a copy.

This Plan is the property of:

PATIENT NAME: _____

DATE OF BIRTH: _____

AGE: _____ **SEX:** _____

DATE OF ALPHA-1 DIAGNOSIS: _____

TODAY'S MONTH/YEAR: _____

**HEALTHCARE PROVIDER
TREATMENT PLAN**

**MY PERSONAL GUIDE TO
ALPHA-1 LIVER DISEASE**



Diagnosis

Alpha-1 Antitrypsin Deficiency

- Confirmed (1 time)
 - Phenotype
 - Genotype
 - Alpha-1 level
- Consider consultation with an Alpha-1 specialist
- Genetic counseling and family testing
- Discussion of membership in the Alpha-1 Research Registry and DNA and Tissue Bank
- Discussion of participation in appropriate clinical trials

**Liver Diagnosis
AAT-related Liver Disease**

- Exclude other liver diseases
- Evaluate for associated conditions
 - Jaundice
 - Portal Hypertension
 - Esophageal varices
 - Bleeding abnormalities
 - Ascites
 - Hypersplenism
 - Encephalopathy
 - Renal Insufficiency (hepatorenal syndrome)
- Referral to Hepatologist to monitor liver function
- Consider Liver Transplant evaluation if signs of liver failure or Portal Hypertension complications

Discuss Alpha-1 diagnosis

- Phenotype_____
- Genotype_____
- Alpha-1 level_____
- Ask about evaluation by a healthcare professional with expertise in Alpha-1
- Discuss genetic and hereditary considerations
- Discuss family testing
- Consider participation in research studies

**Liver Diagnosis
I'm an Alpha with Liver Disease_____**

- Report the following liver symptoms
- Swelling of the abdomen
 - Changes in mental acuity
 - Diarrhea/vomiting
 - Unusual bleeding/difficulty stopping bleeding
 - Yellowing of the skin/eyes
 - Itching
 - Fatigue
- Ask about seeing a liver specialist
 - Discuss status of liver disease and potential for liver transplant

HEALTHCARE PROVIDER

MY PERSONAL GUIDE

**Evaluate for other AAT Related
Medical Conditions**

- COPD
- Gastroesophageal reflux/aspiration
- Necrotizing panniculitis
- Wegener's granulomatosis
- Atypical mycobacteria
- Rare conditions associated with Alpha-1: _____

Report these symptoms

- Changes in ease of breathing at rest/with exertion/with sleep
- Heartburn
- Skin problems such as: rash/itching/pain/eruptions



Health Status Assessments

(annual, at minimum)

Laboratory

- CBC, platelets,
- Albumin
- Vitamin A,D,E,K
- PT, PTT
- ALT, AST, GGTP, Bilirubin total and direct, LDH, Alk.Phos.
- Alpha-Fetoprotein
- Electrolytes, iron
- BUN, Creatinine
- Amylase/lipase
- Hepatitis A,B,C
- HIV
- Ammonia level, if indicated

Laboratory

Ask healthcare provider to discuss lab tests and implication for lung status, liver status, and other conditions

Pulmonary Function Testing

- Complete Pulmonary Function Tests pre- and post-bronchodilator including plethysmographic lung volumes and DLCO
 - Spirometry alone (if morecomplete testing unavailable)
- Six-minute walk with oximetry and titration

Pulmonary Function Testing

Discuss concerns regarding pulmonary function testing

- Difficulties performing test
- Side effects from bronchodilator (if using)
- Health status at the time of testing
- Problems withholding pulmonary medications during testing (if appropriate)



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Radiology/Ultrasound/Endoscopy

- Chest PA and lateral or baseline high resolution CT of chest (1 time only) or follow-up CT of chest (if change in clinical status)
- Bone densitometry (baseline and as indicated)
- Consider Abdominal Ultrasound
- Consider Endoscopy/ERCP
- Consider Liver Biopsy

Medications

Review with emphasis on simplification of the regime, new therapeutics and better self-management by patient

Review the liver implications for specific medications, including OTC medications/vitamins/minerals/dietary supplements

MY PERSONAL GUIDE

Radiology/Ultrasound/Endoscopy

- Discuss concerns regarding radiation exposure
- Discuss results and implication for lung status

Medications

- Bring list of all medications/herbs and dietary supplements to review with physician
- Review the expiration dates on all home medications
- Discuss side effects or issues associated with specific medications including over the counter medications, vitamins/minerals and dietary supplements
- Ask if medications can be reduced or eliminated
- Keep a comprehensive written list of all medications readily available

List your medications here:

HEALTHCARE PROVIDER

MY PERSONAL GUIDE

 **Lifestyle Management**

Immunizations

- ✓ Influenza vaccine
- ✓ Pneumococcal vaccine (q 5 yrs. if COPD)
- ✓ Hepatitis A vaccine
- ✓ Hepatitis B vaccine

Smoking Cessation

- Referral to smoking cessation program
- Nicotine replacement therapy prescribed

Toxic Exposure

Assessment of potential for toxic exposure in the home and workplace

Assess use of alcohol/other liver toxic substances

Keep all of the following up to date:

Immunizations

- ✓ Flu Shot (annual)
- ✓ Pneumonia vaccine (every 5 years if COPD)
- ✓ Hepatitis A vaccine
- ✓ Hepatitis B vaccine

Smoking Cessation

I don't smoke or have a plan in place to stop

- I'm in a smoking cessation program
- I use my nicotine replacement therapy
- I have a strategy in place to avoid second hand smoke

Toxic Exposure

Discuss the potential for toxic exposure in the workplace with supervisor

- Have strategies in place to avoid occupational dust and fume exposure
- As appropriate, have a properly fitted mask
- Know how to access of MSDS at work

I'm aware of those substances in my home or outdoors that are toxic or irritating to my liver/lungs and have a plan to avoid them

- Examples: Cleaning substances

Discuss the risks associated with alcohol consumption and Alpha-1 liver disease



HEALTHCARE PROVIDER

Diet and Nutrition

Identify specific diet recommendations based on type/severity of liver disease symptoms

- Consider dietary consultation
 - Protein intake/restrictions
 - Carbohydrate intake/restriction
 - Fat intake/restriction
 - Frequent small meals
 - Vitamin/mineral supplements
 - Sodium/fluid restrictions
 - Caffeine restriction

Current Weight: _____

Overweight

- Discuss implications of obesity and liver disease
- Consider Dietary Consultation for weight reduction
- Recommendations for exercise programs
 - Home exercise program
 - Pulmonary Rehabilitation

Underweight

- Determine/correct underlying cause
- Dietary consultation with on-going intervention until normal weight restored
- Nutrition plan with consideration of specific dietary supplements and/or medical nutrition intervention
- Discuss need for physical rehabilitation/exercise program

Activity and Fitness: Improvement and Maintenance

Assess current fitness level with potential limitations based on liver symptom severity

- Fatigue: Morning exercise
- Weight training with cirrhosis
 - No high weights; use lower weights with more reps

MY PERSONAL GUIDE

Diet and Nutrition

Discuss specific dietary requirements/restrictions

- Ask about seeing a dietitian

Current Weight: _____

This weight is:

Overweight _____

Underweight _____

Desired weight _____

Overweight

- Develop or enroll in a weight management plan
- Develop or enroll in an exercise program
- Discuss weight the effects of being overweight on your liver

Underweight

- Discuss the need for a nutrition evaluation with healthcare provider
- Discuss the use of vitamins and mineral supplements and potential need for other nutritional interventions
- Discuss exercise limitations until weight stabilized

Activity and Fitness: Improvement and Maintenance

Develop and implement a specific exercise program based on your healthcare providers recommendation, your motivation and perceived level of fitness

- For weight loss _____
- For improved functioning _____
- For maintenance _____

HEALTHCARE PROVIDER

Home Exercise Program recommendations:

- Warm up and stretching
- Muscle strengthening
- Cardiopulmonary (endurance)

Consider Rehabilitation referral

- For endurance and strength
- For ADL and pacing
- For instruction for self-monitoring

Health Insurance

Consider insurance related issues when making referrals, prescribing medications and with other healthcare decisions where cost/reimbursement may significantly impact access to care and services.



Coping and Support Strategies

Assess understanding and acceptance of diagnosis

- Discuss long term implications of diagnosis with chronic disease
- Discuss participation in local support organizations

MY PERSONAL GUIDE

Home Exercise Program

- Request specific recommendations for warm up and stretching, muscle strengthening and cardiopulmonary (endurance) training.
- Date started _____

Discuss the need for a referral to a professional Rehabilitation Program

- Check insurance coverage
- Date started _____

Health Insurance

I am aware of what my current health insurance provides

- Lifetime maximum
- Major medical
- Disability coverage

I have evaluated insurance options based on my age, employment and income

I have considered appropriate supplemental or secondary insurance

I keep careful records and don't hesitate to question denials or coverage issues



HEALTHCARE PROVIDER

Assess for presence of depression

- Consider professional evaluation if symptoms persist or become severe
- Consider antidepressants

Provide opportunity for discussion of issues related to sexuality/sexual performance/dysfunction as related to liver symptoms

- Consider referral to specialist

Discuss potential for transplantation if/when appropriate

End of Life Planning/Advance Directives

Explain, ascertain and document patient's

- Living Will
- Identify responsible family member(s) or holder of durable medical power of attorney
- DNR

Discuss organ donation

MY PERSONAL GUIDE

Report the following symptoms

- On-going feelings of sadness
- Sleep loss/sleeping excessively
- Chronic fatigue
- Weight loss
- Withdrawal from activities/people
- Thoughts of suicide

Discuss issues of sexuality/sexual performance/dysfunction with your healthcare provider

- Energy requirements/breathing
- Body image

Ask for referrals to appropriate support services

Discuss potential for transplantation and preparatory issues

- Selecting a program
- Getting listed
- Discuss potential with family
- Seek support from transplanted Alpha's

End of Life Planning/Advance Directives

Discuss your end of life wishes with your healthcare provider and family

Insure that your wishes are known and carried out by preparing appropriate documents

- Living Will
- Durable medical power of attorney
- DNR

Consider organ donation

PHYSICIAN SIGNATURE: _____

DATE: _____

PATIENT SIGNATURE: _____

DATE: _____

This form is provided as an example only. Always consult your healthcare provider for specific instructions about your individual medical treatments.



This brochure is produced by AlphaNet as part of its Alpha-1 Disease Management and Prevention (ADMAP) program.

AlphaNet is a not-for-profit organization providing disease management services and support to individuals affected by Alpha-1 through a staff of medical professionals and specially trained AlphaNet Patient Services Coordinators, available 24 hours a day, 7 days a week. To learn more about ADMAP or to find the AlphaNet Coordinator nearest you, visit our website (www.alphanet.org).