aHUS SOURCE

Doctor Discussion Guide

A SELF-ADVOCACY HANDBOOK FOR MANAGING ATYPICAL-HUS WITH YOUR HEALTHCARE TEAM

If you've been diagnosed with atypical-HUS or you're the caregiver for someone who has, this guide is for you.

It's been said that self-advocacy "is vital to the independence of individuals with various... diagnoses." We hope this guide helps you to become more informed, take control of your healthcare decisions, and become a more effective self-advocate.

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My appointments

Keeping track of all your appointments in one place can help you stay organized. It also provides a useful record of any specialists you may have been referred to, such as a nephrologist, pulmonologist, or hematologist, and how often you need to see them.

Date	Time	Doctor Name/Specialty	Frequency
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year
			Every __ months/year

Symptom tracker

A written record of your symptoms can be a helpful reference when talking to your doctor. This list is intended as a guide and is not a comprehensive list of all the symptoms that can occur in people with atypical-HUS.

BRAIN

- Confusion — Date: _____ Date: _____ Date: _____
- Stroke — Date: _____ Date: _____ Date: _____
- Seizure — Date: _____ Date: _____ Date: _____

EYES

- Blurred/painful vision — Date: _____ Date: _____ Date: _____
- Blood spots in eyes — Date: _____ Date: _____ Date: _____

HEART

- High blood pressure — Date: _____ Date: _____ Date: _____

LUNGS

- Shortness of breath — Date: _____ Date: _____ Date: _____
- Bleeding/fluid in lungs — Date: _____ Date: _____ Date: _____

DIGESTIVE SYSTEM

- Nausea/vomiting — Date: _____ Date: _____ Date: _____
- Diarrhea — Date: _____ Date: _____ Date: _____
- Abdominal pain — Date: _____ Date: _____ Date: _____

OTHER

- _____ — Date: _____ Date: _____ Date: _____
- _____ — Date: _____ Date: _____ Date: _____
- _____ — Date: _____ Date: _____ Date: _____
- _____ — Date: _____ Date: _____ Date: _____
- _____ — Date: _____ Date: _____ Date: _____

Notes

Lifestyle tracker

Keeping track of how atypical-HUS symptoms are affecting the quality of your life can be a useful tool in conversations with your doctor.

		Not at all	Sometimes	Often
Social activities	I've had to limit my social activities/events.	○	○	○
Employment and education	I've had to limit my work hours or school courseload.	○	○	○
Household chores	I'm not able to do all the housework/food preparation/ yard work I used to do.	○	○	○
Physical activity	I am not as physically active as I used to be.	○	○	○
Mental health	I experience feelings of depression/anxiety/sadness	○	○	○
Other concerns		○	○	○
		○	○	○
		○	○	○

Diagnostic tests

These are some of the tests your doctor may use to monitor your atypical-HUS. Keeping track of test results provides a useful reference for you and can help you have more informed conversations with your healthcare team. This list is intended as a guide and is not a comprehensive list of all the tests that may be used to diagnose and monitor atypical-HUS.

Platelet count

A low level of circulating platelets in your blood can indicate abnormal clotting, which can be an indicator of TMA.

Dates:	Results:

Urine tests

The presence of protein in the urine can indicate kidney damage. The presence of hemoglobin in the urine can indicate hemolysis, or the destruction of red blood cells.

Dates:	Results:

LDH

Elevated lactate dehydrogenase (LDH) is a sign of hemolysis--damaged or destroyed red blood cells--which can be an indicator of TMA.

Dates:	Results:

Creatinine

This test helps to determine how well your kidneys are working. Elevated creatinine can be a sign of kidney impairment.

Dates:	Results:

eGFR

Estimated glomerular filtration rate (eGFR) is a calculation that indicates how well your kidneys are working. It's based on creatinine level and other factors such as age, gender, and weight. Low eGFR can be a sign of kidney impairment.

Dates:	Results:

Genetic testing

Examination of DNA to look for gene mutations known to affect regulation of the complement system. Identifying certain mutations associated with atypical-HUS can be helpful in predicting the likelihood of developing kidney disease or TMA relapse.

Dates	Results:

Other

Dates	Results:

Questions to ask your doctor

It can be hard to remember everything you wanted to ask during an appointment. We've provided some of the most common questions, but be sure to add any others you may have, and use the space provided to record the answers so you have a record for yourself.

What are the most important things you think I should know about atypical-HUS?

What additional tests, if any, do you think I should have?

What are your recommendations for managing my atypical-HUS symptoms?

Are there specialists who are experts in treating atypical-HUS that I should see?

Can atypical-HUS be cured, or will I always have it?

Is atypical-HUS inherited? Do I need to worry if my family members have it?

Other questions

Helpful terms and definitions

ADAMTS13
A disintegrin and metalloproteinase with thrombospondin type 1 motif 13 (ADAMTS13) is a gene that provides instructions for an enzyme that helps your body regulate blood clotting. Too little (≤5%) ADAMTS13 may indicate thrombotic thrombocytopenic purpura (TTP) rather than atypical-HUS.

Complement system
The complement system is a part of the immune system that helps protect your body from foreign substances such as bacteria or other infections. The complement system is made up of a group of proteins found in the blood.

Creatinine
Creatinine is a chemical waste product generated by your muscles and is filtered through your kidneys. Too much (0.7 to 1.3mg/dL for men, 0.6 to 1.1 mg/dL for women) creatinine in the blood can signify impaired kidney function or kidney disease.

eGFR
The estimated glomerular filtration rate (eGFR) is a calculation that measures how well your kidneys are filtering toxins and waste from your blood.

Genetic Counselor
Someone who specializes in helping people understand the medical, psychological, and familial implications of genetic contributions to disease.

Hematologist/Oncologist
A doctor who specializes in blood disorders.

Hemolysis
The destruction of red blood cells in the body.

LDH
Lactate dehydrogenase (LDH) is an enzyme that is found in almost all of your body's cells and is released into your blood when cells are damaged or destroyed. Elevated LDH can be an indicator of hemolysis.

Nephrologist
A doctor who specializes in kidney disorders.

Neurologist
A doctor who specializes in the brain and central nervous system.

Platelets
Platelets (or thrombocytes) are fragments of cells whose function is to help your blood clot to stop bleeding.

Red blood cells
Red blood cells (or erythrocytes) deliver oxygen from your lungs to the rest of your body. They also transport carbon dioxide from your body's tissues back to your lungs, where it is exhaled.

Schistocyte
A schistocyte is a fragment of a damaged or injured red blood cell.

TMA
Thrombotic microangiopathy (TMA) is a group of medical disorders that results in clots and inflammation in various small blood vessels throughout the body. This results in injury to organs, such as the kidneys.

TTP
Thrombotic thrombocytopenic purpura (TTP) is a kind of TMA (see above). TTP is a rare blood condition that can cause blood clots that may lead to serious medical problems.

Triggers
A trigger is a precipitating event that causes the onset of another condition. Triggers that may cause the symptoms of atypical-HUS include infections, certain medications, being pregnant, or having another condition, such as malignant hypertension.

Finding Support

Your physical symptoms can sometimes feel all-consuming, but paying attention to your psychological and emotional well-being can be an important part of adjusting to life with atypical-HUS.

You may want to ask your doctor for a referral to one or more support resources in your area.



Mental health counseling



Caregiver support programs



Community groups

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