

NEWLY DIAGNOSED

Cold Agglutinin
Disease Foundation

CARES

Community-Awareness-Resources-Education-Support

Welcome to our Cold Agglutinin Disease (CAD) family! We have been where you are. Please know that this website was created as a non-profit endeavor by and for CAD patients and their families and care partners. We are dedicated to providing you with the basic tools, resources and support at the beginning of your own personal journey of learning about CAD and how to live with this rare disease.

We suggest you consider this disease a chronic one to be managed, and it CAN be managed with a few adaptations. Its symptoms might fluctuate in duration or severity and can be treated, but for now, there is no known treatment, which permanently “cures” the underlying condition. On the other hand, some promising clinical trials for CAD are in progress as we write this. Many of our website visitors are engaged in them, and some have shared their experiences in our Facebook group CADDy CHATTER <https://www.facebook.com/groups/192296905079/>. In addition, there is one off-label treatment called Rituxan that you might want to discuss with your doctor.

That said, let’s be frank: It can be difficult, confusing and overwhelming to deal with a diagnosis of a rare disease such as CAD. Statistically, we are only a tiny percentage of all auto-immune anemias, which in turn are a sub-category within the larger group of blood disorders. As a result, CAD is often overlooked, misdiagnosed or confused with other diseases. Since it is estimated that there might be no more than 10,000 persons with CAD throughout the whole Western Hemisphere, many healthcare providers will never have the chance to treat or diagnose a CAD patient during their entire practice. Complicating the situation is the unfortunate fact that hospital and commercial labs are often totally unfamiliar with the necessary special collection and handling blood testing protocols to ensure accurate results for CAD patients.

On the bright side, you are unique—literally one (or ten or twenty, give or take) in a million. Now, where to begin? Here is what we suggest:

Knowledge is power!

This website contains basic facts about CAD as well as valuable links and up-to-date information about treatment options. Your experience with CAD will probably begin with a course of regular blood tests, which most doctors recommend to monitor your condition, and you will want to become familiar with the specific tests used in lab reports which are of particular concern to CAD patients. One of these is a Coombs test, which is done to find certain antibodies that attack red blood cells. Normally, antibodies bind to foreign substances, such as bacteria and viruses, and cause them to be destroyed, but in our case, the antibodies are confused and attack our red blood cells. Another is a haptoglobin test, which can confirm if you have hemolytic anemia. A CBC test is a lot of different blood tests that measure your hemoglobin, various liver enzymes, and other blood-related properties. Your hospital, medical system, or doctor may make the results of your tests available to you. If you do not understand the more complex medical terms used to explain CAD and its treatment, do not hesitate to ask your provider or someone with an appropriate medical background to explain them.

Particularly just after diagnosis or when considering treatment, it is helpful to develop a list of questions and concerns in writing to discuss with your doctor. If necessary, have a responsible person or care partner accompany you to doctor appointments to help you remember and write down all the new information you will wish to absorb.

FYI: One silver lining for CAD patients is that one of the treatments recommended for management of our lowered hemoglobin levels is folic acid, an inexpensive vitamin supplement available over the counter. In fact, the multi-vitamins you already take probably contain much of your recommended daily dosage. Folic Acid helps our bone marrow to make red blood cells. Vitamin B-12 works closely with Folic Acid in red blood cell production, so you may want to take a daily B-12 sublingually for best results. For reasons more fully explained

elsewhere on this site, many CAD patients are additionally recommended to take a daily low dosage aspirin, which of course is also inexpensive and available without prescription.

[Choose a specialist to become part of your medical team](#)

If you have been diagnosed with CAD by a family doctor or internist, you might wish to seek a referral to a hematologist/oncologist who specializes in treating blood disorders (and preferably one who is board certified in that specialty). Ideally, they will have some familiarity with CAD and can determine whether to run additional tests, including but not limited to additional blood or diagnostic tests such as bone marrow biopsies. These procedures can rule out or identify other blood disorders and related diseases, which may also need treatment, and of course, you will want the specialist to discuss the best current treatments and possible clinical trials for you.

[Print out and carry important information](#) (see following pages) which includes:

- A downloadable PDF printout of special instructions to give to your lab test technicians for collecting and handling your blood specimens;
- A handout summarizing CAD for the times you aren't able to describe this disease and/or need to communicate the basic important concerns about CAD to providers, care partners and others.

[Consider getting a Med Alert bracelet](#) naming our disease and providing clear instructions to first responders about the need for room temperature and warmed fluids for emergency IVs and blood transfusions. Many emergency medical professionals have never heard of CAD. This is critical information which could save your life.

[How do I explain this “invisible” disease to family and friends?](#)

CAD is a rare disease and as such, quite different from more obvious physical disabilities or common illnesses with which most people are familiar (such as heart disease or diabetes). Even those CAD patients who are afflicted to the point that they are deemed to be legally disabled for work or who suffer from extreme fatigue might not appear visibly disabled to an onlooker, and it can be awkward, if not embarrassing, to explain why we must avoid cold drafts, foods and beverages, and why some of us need to wear heavy sweaters, hats and gloves, even in temperate climates. Not to mention explaining why our bodies, especially our noses, toes and fingers turn blue or purple in climates which others find perfectly comfortable.

Many of us with CADs have learned to provide a quick description for our complex condition: For example, we might say we have an auto-immune disease that makes us “allergic” to the cold, or we might explain that cold weather causes our anemia and fatigue which can't be cured simply by taking iron supplements. Last but not least, the explanation for our cold-related blue and purple extremities can be better understood if likened to Raynaud's disease.

To those who live with or care for us, we should also add that we must closely monitor any symptoms that might suggest blood clots or strokes, for which we are considered at higher risk. Family members and care partners need to learn about CAD in case we require medical attention of any kind.

[LIVING WITH CAD – ALL OUR STORIES](#)

Simply put, CAD does not affect each of us in the same way. Some CAD patients have only moderate symptoms; some will find the disease changing in severity as we age, and others must take a more aggressive and proactive approach to their symptoms from the very onset. Statistics show that most of us are mature adults when diagnosed, often coping with other age-related health issues that have no connection to CAD, but there are younger CAD patients who may face different personal challenges than their seniors.

One of the best ways to get perspectives on your own journey as well as some plain practical advice about managing your CAD is to hear the stories of others affected by it. Videos relating the first-person stories by CAD patients, family members and their caretakers can be found here: <https://coldagglutininidisease.org/our-stories>. If you are interested in sharing your story and will allow us to share it with others on our website, please fill out your profile here <https://coldagglutininidisease.org/share-your-story>.

TAKE THIS CARD TO YOUR LAB OR HEALTH CARE PROFESSIONAL

COLD AGGLUTININ DISEASE – INSTRUCTIONS FOR BLOOD DRAWS

I have Cold Agglutinin Disease/Cold Autoimmune Hemolytic Anemia, and to get a usable blood draw for a CBC test and avoid agglutination of my blood, the blood sample must be kept at 37 degrees Celsius until tested.

1. Please warm the tube for the CBC test.
2. Draw blood.
3. Continue to keep the tube warm with baby heel warmers or another warming device.
4. Take to lab immediately.
5. Ask the lab to test the blood stat.

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ESSENTIAL QUESTIONS TO ASK YOUR DOCTOR



TAKE CHARGE
of your CAD Diagnosis
it starts with a conversation

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<input checked="" type="checkbox"/>	What is Cold Agglutinin Disease or Cold Autoimmune Hemolytic Anemia?	<input checked="" type="checkbox"/>	What are the risks of this disease?
<input checked="" type="checkbox"/>	What is your experience with CAD?	<input checked="" type="checkbox"/>	What will I need to do to take care of myself?
<input checked="" type="checkbox"/>	Will I get worse as time goes on?	<input checked="" type="checkbox"/>	Will I need more blood tests? How often?
<input checked="" type="checkbox"/>	What will the blood tests tell us?	<input checked="" type="checkbox"/>	Will you send me copies of my tests?
<input checked="" type="checkbox"/>	How many CAD patients do you have?	<input checked="" type="checkbox"/>	What treatments are available?
<input checked="" type="checkbox"/>	What are the side effects of the treatments?	<input checked="" type="checkbox"/>	How does the treatment work?
<input checked="" type="checkbox"/>	What is the success rate of the treatment?	<input checked="" type="checkbox"/>	Are there clinical trials available to me?



Blood Test Tracker:

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DATE:		CBC With Differential	
Haptoglobin			WBC Count
Lactate Dehydrogenase			RBC Count
Comprehensive Metabolic Panel			HGB
	Sodium, S		Hematocrit
	Potassium		MCV
	Chloride		MCH
	CO2		AMCHC
	Glucose		RDW
	Bun		Platelet
	Creatinine, S		MVP
	Protein, Total		% Immature Granulocytes
	Albumin, S		% Neutrophils
	Calcium, Total		% Monos
	Bilirubin, Total		% EOS
	Alkaline Phos		% BASOS
	AST (SGOT)		Absolute Immature Granulocytes
	ALT (SGPT)		Absolute Neutrophils
	Globulin		Absolute Lymphs
	Anion Gap		Absolute Monos
	GFR – Non-African American		Absolute EOS
	GFR – Non-American		Absolute BASOS
			NRBCS

