

Cold Agglutinin Disease (CAD)

1. What is Cold Agglutinin Disease?

Cold Agglutinin Disease (CAD) is a rare condition. When you have CAD, your body's immune system produces autoantibodies that destroy your red blood cells. These autoantibodies, called **cold agglutinins**, are made when your body is exposed to very cold temperatures.

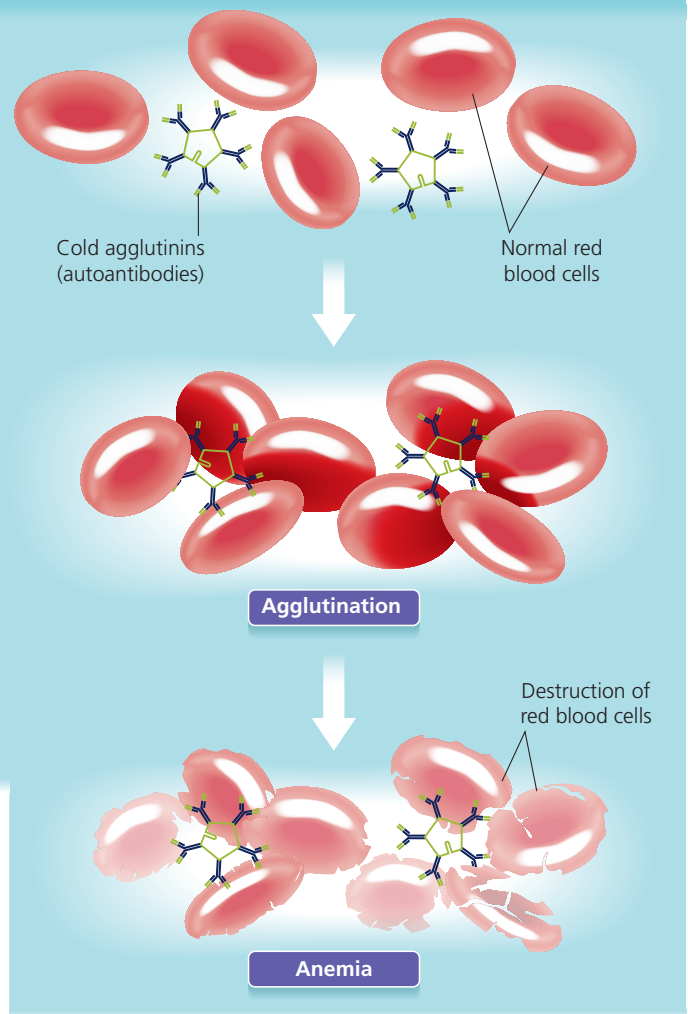
Cold agglutinins stick to your red blood cells, causing them to clump together. This process is called **agglutination**. Agglutination leads to the destruction of the red blood cells in a process called **hemolysis**. Hemolysis causes **hemolytic anemia** and other symptoms. Triggers for hemolysis include cold temperatures and bacterial and viral infections.

Cold agglutinins exist in everybody, but in people diagnosed with CAD, the agglutinins can react at just below body temperature.

agglutination – when red blood cells clump together

anemia – a lack of red blood cells to transport oxygen around the body

hemolysis – the breakdown of red blood cells



2. Is there a cure?

There is no cure for CAD at this time, but treatments exist to help manage the symptoms and reduce the impact on your daily life.

3. How will CAD affect me?

Your red blood cells carry oxygen around your body. When your red blood cells are destroyed faster than your body can replace them, you develop hemolytic anemia.

The symptoms of **anemia** can include fatigue, pale skin, shortness of breath, or heart palpitations. People with CAD have a greater chance of having blood clots, strokes, and heart issues than the average person.

The symptoms of CAD can include:

- difficulty thinking clearly ('brain fog')
- red or purple discoloration (acrocyanosis) of fingers, toes, nose, earlobes, cheeks, and lips
- pain and discomfort in body parts affected by acrocyanosis
- cold-induced fatigue
- tea-colored urine

CAD symptoms vary between patients, though everybody with a CAD diagnosis has great sensitivity to colder temperatures.



Red or purple discoloration to the hands and other body parts is called acrocyanosis.

It's a common symptom of CAD and can be very painful.

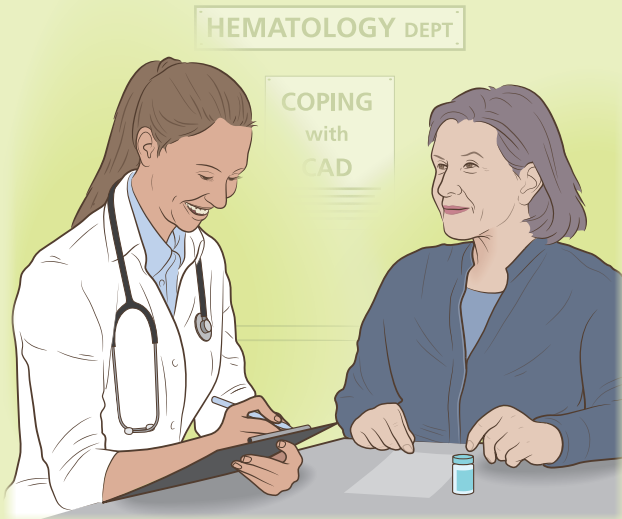
4. How did I get CAD?

CAD can be caused by other conditions, or it can develop without any known cause. People over the age of 50 are more likely to develop CAD, and it's slightly more common in women than men. The cause of **Primary CAD** is unknown. **Secondary CAD** can be caused by other health conditions such as certain blood cancers, viruses, and infections.

Treatment for CAD

5. The importance of finding a knowledgeable clinician

Because CAD is rare, it's important to find a doctor who understands this condition well. A hematologist, a specialist in blood disorders, is often the best type of clinician to help manage CAD. They can help you understand your condition, recommend the right tests, and guide your treatment.



6. Lab tests after diagnosis

After you're diagnosed with CAD, regular blood tests will help track how your condition is affecting you. These may include a Complete Blood Count (CBC) to measure your red blood cell levels. Your doctor may also check for signs of anemia and measure your hemoglobin levels as well as other readings important to CAD. A Comprehensive Metabolic Panel (CMP) will test bilirubin levels, and other chemical imbalances caused by CAD. Bilirubin is a substance released when red blood cells break down.

A red blood cell normally lives for about **120 days** before it breaks down and is replaced by a new one.

In CAD, however, red blood cells are destroyed too early.

7. What is the treatment?

Avoiding cold temperatures is very important, since cold exposure causes the clumping of red blood cells. If your symptoms are severe and affecting your quality of life, you may be offered a treatment that will reduce hemolysis. These treatments need to be kept at room temperature, and they will suppress your immune system.

Blood transfusions may be necessary if you experience a severe drop in hemoglobin. It is very important that the transfused blood is warmed to avoid triggering agglutination during transfusion.



8. What can I do to manage the condition?

To manage CAD, it's very important that you **avoid exposure to cold** and to bacterial and viral infections. You may find that you are no longer able to do certain hobbies and pastimes as a result.

You should always dress warmly in layers, especially covering your hands, feet, ears, nose, and mouth.

Cold environments can cause agglutination. This will lead to more severe symptoms.

It's also important to stay in regular contact with your doctor. Help, advice, and support are available at the CAD Foundation and other patient advocacy groups.

Where can I find further information and support?

Cold Agglutinin Disease Foundation

www.coldagglutindisease.org

www.facebook.com/CADForg

CADdy Chatter www.facebook.com/groups/192296905079

www.facebook.com/CADunraveled

www.facebook.com/groups/CADdisease