

ALPHA-GAL SYNDROME PATIENT FACTSHEET



Alpha-gal syndrome (AGS) is a serious, potentially life-threatening allergy to alpha-gal (galactose-alpha-1,3-galactose), a sugar found in most mammals. Products made from mammals or containing ingredients made from mammals, including many foods and drugs, can also contain alpha-gal.

Tick bites cause AGS. In the U.S., most cases are caused by lone star ticks, which are most common in the southern, midwestern, and mid-Atlantic United States. Internationally, other ticks cause AGS.



**Newly diagnosed?
Start here**

MAMMALS

Mammals are animals that feed their young milk. Most are furry. Examples include cows, pigs, sheep, goats, deer, squirrels, and rabbits.



SYMPTOMS OF AGS



Alpha-gal reactions usually occur 2-8 hours after people eat foods containing alpha-gal. Some non-food exposures - for example, some intravenous medications - can cause immediate reactions. Symptoms can range from mild to severe. Note that people with AGS often do not react after every exposure. Symptoms can change for an individual if they get more tick bites.

Symptoms can include:

- Hives or itchy rash
- Nausea or vomiting
- Severe stomach pain
- Heartburn or indigestion
- Diarrhea
- Cough, shortness of breath, or difficulty breathing
- Drop in blood pressure
- Swelling of the lips, throat, tongue, or eye lids
- Dizziness or faintness
- A combination of symptoms referred to as anaphylaxis

Learn how to recognize and respond to the full range of allergic symptoms, especially anaphylaxis.



Recognizing and responding to anaphylaxis

[FARE's Food Allergy and Anaphylaxis Care Plan](#)

FOODS TO AVOID

All foods made from mammals or with mammal-derived ingredients may contain alpha-gal. However, you may not need to avoid all of these foods. Work with your healthcare provider to determine what foods to avoid based on your sensitivity and preferences.

Avoid:

- Mammal meat, like beef, pork (including bacon), lamb, venison, bison, goat, and rabbit
- Mammal organs, like liver, kidneys, intestines (tripe), and Rocky Mountain oysters
- Mammal fat, like lard and tallow
- Foods made from the tissue or fluids of mammals
- Mammal broth, bouillon, stock and gravy
- Flounder roe (nitsuke)

Discuss with your provider foods you *may* need to avoid:

- Dairy, like milk, yogurt, cheese, butter
- Gelatin
- Mammal byproducts
- Carrageenan (made from red algae that produce alpha-gal)
- Some natural flavorings

How to figure out your trigger foods:

Because alpha-gal symptoms are delayed, it can be difficult to figure out the culprit. Track the time and date of your food and symptoms. Share this with your healthcare provider.



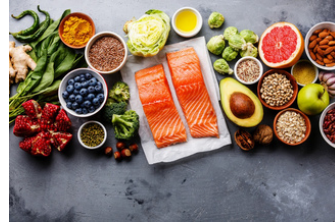
FIG App: Food scanner & guide
foodisgood.com

Buying Safe Foods

- Download the FIG App and use the barcode scanner to see if foods contain alpha-gal.
- Beware of poultry sausages made with mammal casings.
- When eating out, watch out for lard in fry oil and cross-contact with mammal meat.
- **Read food labels!**

FOODS YOU CAN EAT

- Fish and other seafood, except flounder roe (eggs)
- Poultry, like turkey, chicken, and duck
- Eggs
- Emu and ostrich (birds whose meat tastes like beef)
- Pork from Revivacor's genetically modified GalSafe pigs
- Fruits, vegetables, and grains
- Nuts, seeds, beans, lentils, tofu, tempeh



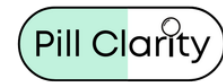
MEDICATION USE



Many drugs, vaccines, and other medical products contain mammal-derived ingredients. Some medications should be avoided or used with caution. Other products like gelatin capsules, gelcaps, and tablets containing magnesium stearate or lactose are often tolerated.

Sometimes the danger of not using a medical product outweighs the risk of a reaction (e.g., antivenom, rabies vaccine).

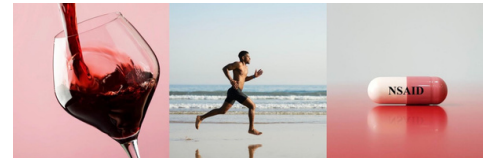
Seek your healthcare provider's advice about the use of specific medical products, especially if you take thyroid medication, pancreatic enzymes, infliximab (Remicoid), ustekinumab (Stelara), or if you need a vaccine, antivenom, heparin, or medical procedure.



Pill Clarity can help you find medications that are free from animal-derived ingredients.

THINGS THAT CAN MAKE YOUR REACTIONS WORSE (ALSO CALLED "COFACTORS")

Cofactors such as alcohol and exercise can make reactions more likely or more severe. For example, if you drink wine with dinner or jog after lunch, you are more likely to react to any alpha-gal you consumed. Other cofactors include NSAIDs (like Advil, Aleve, Motrin, Naprosyn, diclofenac, ibuprofen).



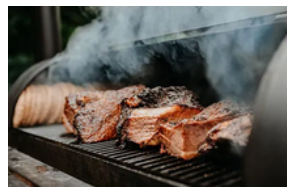
OTHER EXPOSURES



Cosmetics, personal care products, and household products can also contain alpha-gal. If you react to them, try vegan products. Check for carrageenan, especially in toothpaste.

Dander, waste, saliva, blood, and amniotic fluid from pets, livestock, and game contain alpha-gal. Most people can keep their pets. Farmers may need to take special precautions, especially during calving. Hunters need to avoid direct exposure to blood.

Some people react to airborne alpha-gal, especially fumes from cooking meat.



MANAGING YOUR REACTIONS

Your provider will work with you to develop a plan for managing both severe reactions and milder symptoms, such as a few hives or mild GI symptoms. Your plan may include the use of antihistamines, epinephrine autoinjectors, and possibly steroids, oral cromolyn, or omalizumab (Xolair).

Remember to keep your emergency medications with you when you go out!



FARE's Food Allergy and Anaphylaxis Care Plan



AVOID TICK BITES

New bites can make your AGS worse.

If you avoid new tick bites, you may eventually be able to add mammalian foods back into your diet under the supervision of your allergist.



TickSmart Tips

ADDITIONAL RESOURCES



Islands Public Health.com



Alpha Gal Information.org

Thank you AGI.org for the handout template!



CDC AGS Website



MA DPH Website