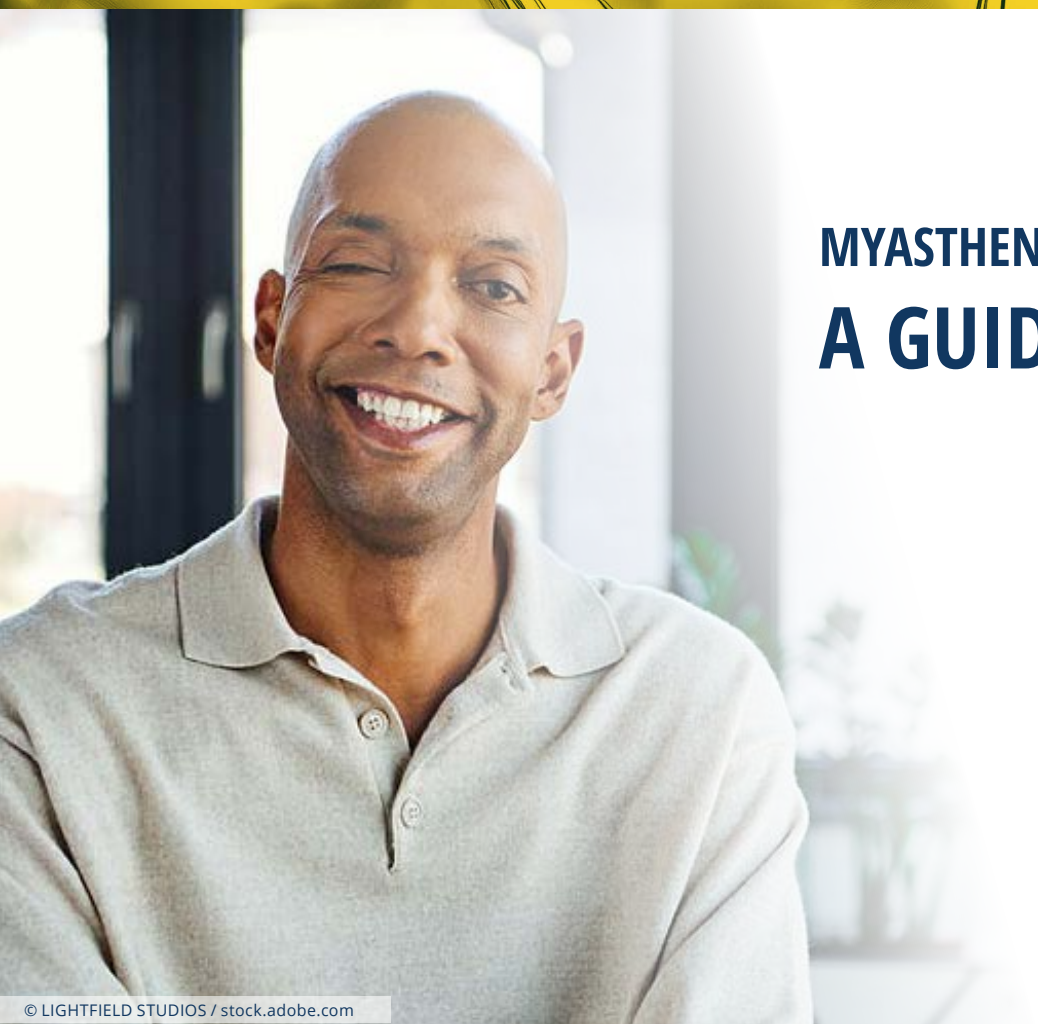
gMG AWARENESS ADVANCES ACTION



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MYASTHENIA GRAVIS ESSENTIALS:
A GUIDE FOR ADULTS

This guide is designed for adults who have been diagnosed with myasthenia gravis (MG). Being diagnosed with a chronic condition such as MG can feel overwhelming, but understanding your condition and treatment options can help you take control of your health.

In this guide, you will find essential information about MG, including what causes it, how it affects the body, available treatment options, and tips for managing daily life with the condition. It also includes practical advice on recognizing symptoms, avoiding potential triggers, and preparing for an MG emergency.

To help you navigate your care, this guide also includes a **consultation companion**, which provides suggested questions you can ask your healthcare provider. These questions can help you better understand your diagnosis, explore treatment options, and ensure that you receive the support you need.

Remember, MG affects everyone differently, and working closely with your healthcare team is key to finding the best management plan for you.

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What is MG?

MG is a chronic autoimmune disease that causes muscle weakness and tiredness. It occurs when there is impaired communication between your nerves and muscles.

The symptoms of MG can include:

- Drooping eyelids
- Blurred or double vision
- Difficulty making facial expressions
- Trouble chewing
- Slurred speech
- Difficulty swallowing
- Difficulty breathing
- Weakness in arms, hands, fingers, legs, or neck
- General tiredness and fatigue
- Mobility problems

The two main types of MG are generalized MG (gMG) and ocular MG. gMG causes people to experience muscle weakness throughout the body, including the eyes. Ocular MG affects the eyes only.

The severity of MG varies from person to person and can fluctuate greatly. Some people may experience mild, manageable symptoms, whereas others may have more significant challenges. MG is often called *snowflake disease* because, like snowflakes, no two cases are exactly alike.

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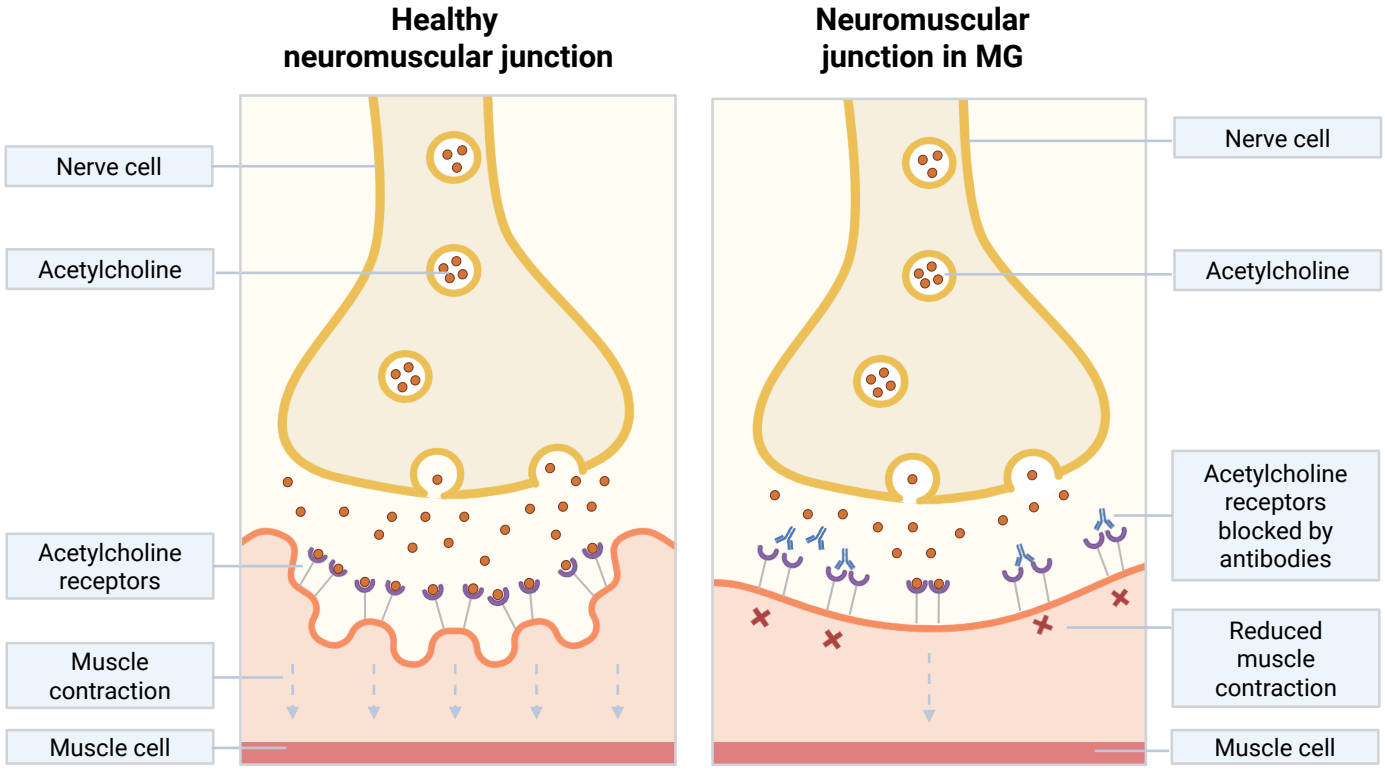
What causes MG?

MG occurs when your immune system attacks the **connection** between your nerves and muscles.

When your brain wants to move a muscle, it sends a signal through **nerves**. At the end of the nerve, a substance called acetylcholine is released. This substance travels across a tiny gap (the **neuromuscular junction**) and attaches special receptors on the muscle. When enough acetylcholine binds to these receptors, the muscle contracts, which allows movement.

Your immune system produces substances called **antibodies** that protect you from infection and disease. In MG, the immune system mistakenly makes harmful antibodies that block, change, or destroy the receptors that attach to acetylcholine on the muscle. This stops acetylcholine from attaching to its receptor, meaning that the muscle does not receive its signal and becomes weak.



What terms may I hear related to antibodies?

The main antibodies involved in MG are called **acetylcholine receptor (AChR)** and **muscle-specific tyrosine kinase (MuSK)**. Around 10% of patients have no detectable antibodies, which is called **seronegative MG**. The symptoms of seronegative MG are similar to antibody-positive MG.

It is believed that seronegative MG is caused by antibodies that cannot yet be tested for or have not yet been identified. If your test results do not show detectable antibodies, do not panic – your doctor will still be able to diagnose MG with electrical testing and other supportive tests and treat MG based on your symptoms and medical history.

How is MG treated?

There is no cure for MG, but several treatment options can help manage symptoms and improve quality of life. With the right treatment plan, many people with MG can control their symptoms, maintain daily activities, and prevent serious complications, and some may achieve remission. Everyone's experience of MG is different, and so your treatment plan will depend on your specific symptoms and individual case. You may receive multiple treatments at once.

Treatment	How it works
Surgery	
Thymectomy	Thymectomy is surgery to remove the thymus gland. The thymus gland is located behind the breastbone and is associated with the immune system. The thymus gland plays an important role in MG.
Medications	
Acetylcholinesterase inhibitors (e.g., pyridostigmine bromide and neostigmine bromide)	Acetylcholinesterase inhibitors improve the communication between your nerves and muscles. They increase the levels of acetylcholine, which helps muscles contract and can improve muscle strength.
Corticosteroids (e.g., prednisone, prednisolone) and other, nonsteroidal immunosuppressants (e.g., azathioprine, mycophenolate mofetil, cyclosporine)	Immunosuppressants reduce the immune system's activity, which lessens the production of certain cells in your blood (called T cells and B cells). These cells play a role in the immune response and antibody production. These medications help lower the number of abnormal antibodies that interfere with the connection between your nerves and muscles. Immunosuppressants can be steroidal (corticosteroids) or nonsteroidal. Corticosteroids and/or other immunosuppressants are typically used when additional treatment is needed beyond acetylcholinesterase inhibitors.
Targeted treatments	
Complement inhibitors (e.g., eculizumab, zilucoplan, ravulizumab-cwvz)	Complement inhibitors are a type of treatment that helps reduce the immune system's attack on the connection between the nerves and muscles. Complement inhibitors work by blocking a part of the immune system called the complement system, which plays a role in the damage to this connection. These treatments can help improve muscle strength and reduce symptoms.
Neonatal Fc receptor (FcRn) inhibitors (efgartigimod, rozanolixizumab, nipocalimab)	FcRn inhibitors are a type of treatment that helps lower the levels of harmful antibodies in your blood. FcRn inhibitors work by blocking a natural process in your body that allows these harmful antibodies to stay in your system longer. By reducing their levels, this treatment can help improve symptoms and support muscle function.
B-cell-directed treatments (e.g., rituximab)	B cells are a type of white blood cell that helps produce antibodies and plays a role in the immune response linked to MG. Treatments that target B cells may help reduce this immune response and lower the levels of abnormal antibodies that contribute to MG symptoms. If you are prescribed this medication, you will receive it as a drip (IV infusion) that is inserted into your vein.

Treatment	How it works
Plasma exchange and immunoglobulin treatment	
Intravenous immunoglobulin (IVIg)	IVIg is a treatment made from healthy antibodies collected from donated blood. It is given through a drip (IV infusion) into a vein, usually in a hospital or clinic. IVIg temporarily alters the immune system by reducing the levels of abnormal antibodies that cause MG symptoms.
Plasma exchange (plasmapheresis)	Plasma exchange is a procedure that removes abnormal antibodies from the blood. A machine separates and replaces the plasma (the liquid part of your blood), helping to quickly reduce MG symptoms. This is mostly used for short-term treatment in emergency cases or before surgery.

It is important to take your MG medication as prescribed. Do not stop or change your treatment without speaking to your healthcare provider. Stopping medication suddenly can cause symptoms to worsen or lead to complications.

If you experience side effects or have concerns about your treatment, talk to your doctor – they can help adjust your medication or explore other options to best manage your condition safely.

Living with MG

The symptoms of MG vary from person to person and can be challenging to manage. However, there are several strategies that can help you better manage your symptoms:

- **Plan activities around your energy levels.** Do more energy-consuming activities when you feel strongest and take breaks when needed. When your energy levels are low, focus on resting and conserving your energy levels
- **Avoid triggers**. Infections, stress, heat, and certain medications can worsen symptoms. If heat affects you, try to stay cool. Check with your healthcare provider to ensure that your vaccinations are up to date but avoid live vaccines if you are taking immunosuppressants
- **Practice good sleep habits.** Getting enough rest can help you manage fatigue and muscle weakness
- **Adjust your eating routine.** Eat smaller, more frequent meals when your energy levels are highest. Consider timing mealtimes around when your medication seems most effective. If swallowing is difficult, opt for softer foods and thickened liquids. Aim for a balanced, nutritious diet to support overall health and wellbeing
- **Set realistic goals about exercise**. Staying active with MG can be challenging, but it is possible to maintain an active lifestyle. Begin with gentle activities, and slowly increase the intensity based on your energy levels. Focus on low-impact exercises that help maintain mobility and strength without overexerting yourself. Listen to your body, set realistic goals, and find what works best for you
- **Use assistive devices if needed.** Tools such as grab bars or mobility aids can help with daily tasks. Safety railings can also be used for support in bathrooms and near steps. Take precautions to minimize fall risks
- **Communicate your needs.** Let family, friends, and colleagues know how they can support you. Do not be afraid to ask for help when you need it
- **Join a support group.** Connecting with others who have MG can provide helpful advice and emotional support

Preparing for emergencies and myasthenic crises

Myasthenic crisis affects around 20% of people with MG. It occurs when the breathing muscles get too weak to move enough air in and out of the lungs. The person is unable to breathe, and a machine (ventilator) is necessary to help them breathe.

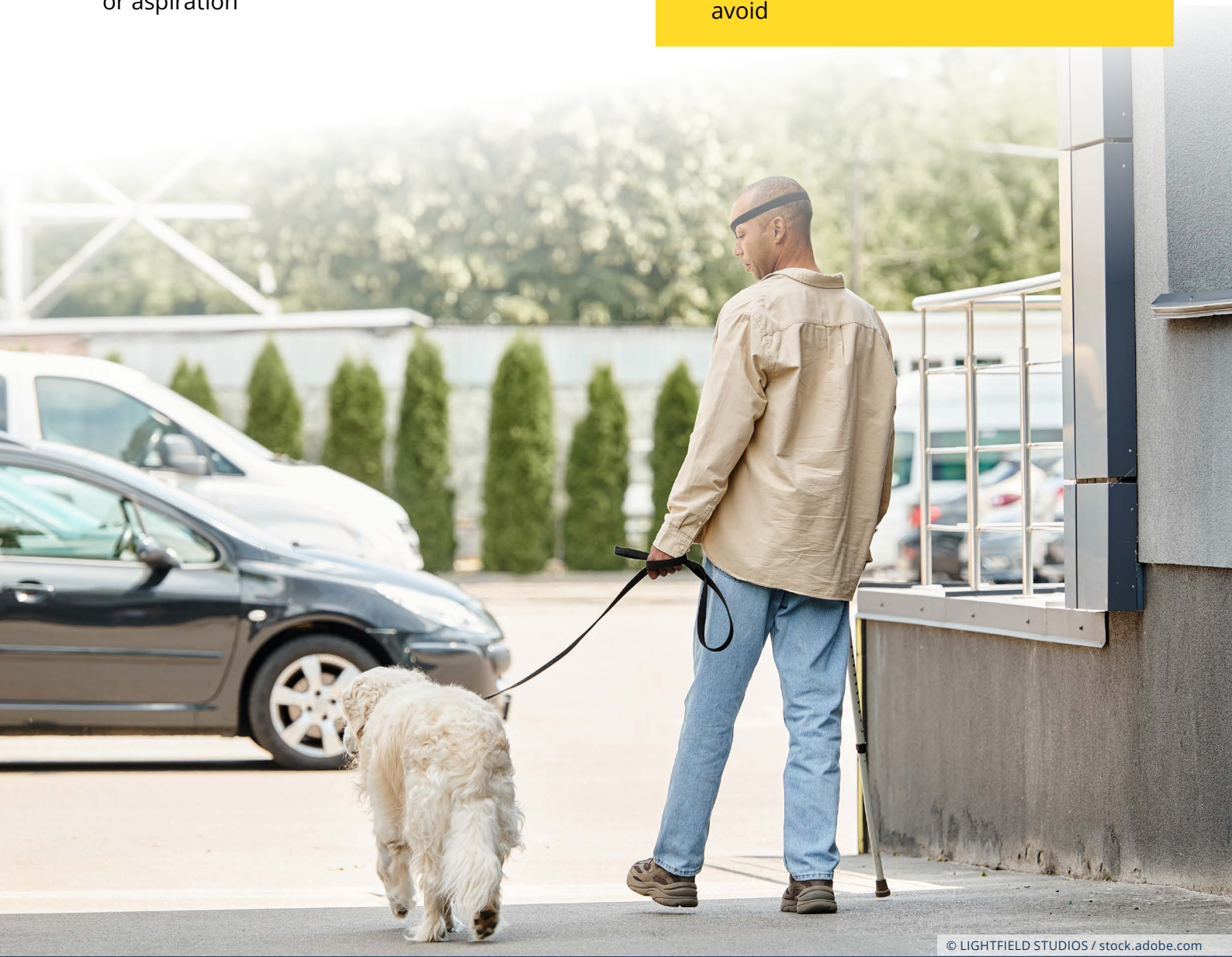
Although myasthenic crisis is rare, it is important to be prepared in case of an emergency.

Recognizing the signs of a flare-up may prevent you from going into crisis, so always notice how you are feeling and seek emergency attention if you experience any of the following:

- Significant shortness of breath or difficulty taking a deep breath
- Trouble speaking clearly due to weakness
- Severe difficulty swallowing, leading to choking or aspiration

Myasthenic crisis preparation checklist

- **Have an emergency plan.** Talk to your healthcare provider about what to do in a crisis and when to seek urgent care
- **Consider carrying an emergency alert card in your wallet or wearing an alert bracelet.** This helps emergency responders and medical professionals know that you have MG and how to treat your myasthenic crisis
- **Pack the essentials.** Keep a small bag ready with toiletries, comfortable clothes, spare medications, important medical documents, and anything else you might need for a hospital stay
- **Keep important documents handy.** Have a list of emergency contacts, your medications (including dosages), medical history, and a list of cautionary drugs to avoid



Consultation companion

When managing MG, it is important to have open communication with your healthcare provider. Asking the right questions can help you understand your treatment options, manage symptoms, and maintain a good quality of life. Do not hesitate to ask your healthcare provider for guidance and resources to help you navigate your journey with MG. Some suggested questions include:

My questions	My answers
What can I do if I experience difficulty swallowing or speaking?	
What do I need to know about taking my medication (e.g., How often should I take it? When should I take it? Should I take it with a meal?)	
Are there any specific side effects I should watch out for with my medication?	
How will we monitor my condition to adjust my treatment plan over time?	
Are there any lifestyle changes I should make to help my treatment work better?	
Are there any support groups or resources for people with MG that you recommend?	
How do I know when my breathing, speaking, swallowing, or weakness warrant medical attention?	
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Space for patient question 1	

What to expect from your doctor

The questions your healthcare provider asks will depend on your specific situation. However, your provider is likely to ask about your symptoms, their severity, and potential triggers to help guide treatment. Being prepared to answer these questions can help ensure a more effective discussion with your provider. Some common questions may include:

- Do your symptoms fluctuate throughout the day or worsen with activity?
- How are your symptoms impacting your daily life?
- Is there anything that seems to improve your symptoms?
- Does anything appear to worsen your symptoms?
- Have you tried any treatments so far? If so, how effective have they been?
- What are your goals for treatment (e.g., symptom relief, improved mobility, reduced fatigue)?
- Do you have a support system in place, such as family, friends, or caregivers, who can help you manage your condition?

Looking for support?

Navigating life with MG can feel overwhelming, but you do not have to do it alone. Connecting with advocacy groups, patient communities, and trusted medical organizations can provide valuable information, emotional support, and access to the latest research. Whether you are newly diagnosed, have been diagnosed for a long time, or are a caregiver, these resources can help you better understand MG and find a supportive community.

Myasthenia Gravis Foundation of America
https://myasthenia.org/

European Myasthenia Gravis Association
https://www.eumga.eu/

MyAware (UK)
https://www.myaware.org/

Myasthenia Gravis Association
http://www.mgakc.org/

National Organization for Rare Disorders (NORD) – MG information
https://rarediseases.org/rare-diseases/myasthenia-gravis/

Myasthenia Gravis Society of Canada
https://www.mgcanada.org/

Myasthenia Gravis Support Group New Zealand
https://myastheniagravisnz.wordpress.com/

Australian Myasthenic Association
https://myasthenia.org.au/