Gregory W. Fulton ALS Center

# ALS Medications

Barrow Neurological Institute

This handout is to review the medications that are currently FDA approved for the treatment of ALS. It is important to understand that the goal of these medications is to slow progression of the disease. As progression is very difficult to ascertain in ALS, you should not expect to notice improvement or feel any differently on these medications. All of these medications work differently so they can be taken together. Please discuss your treatment plan with your provider, including prescriptions, supplements, and research therapies.

**Riluzole** is a glutamate inhibitor, which is thought to be neuroprotective as excessive glutamate can damage the motor neurons. This was FDA approved in 1995. It can can modestly extend life expectancy. It is generally well tolerated and affordable. Side effects include fatigue, nausea, dizziness, and elevation of liver enzymes. These side effects usually resolve after a few weeks. We monitor your liver enzymes via blood test for the first three months after starting therapy. It is available as a tablet, liquid, and oral film and is taken twice daily.

**Radicava** is a free-radical scavenger that prevents oxidative stress damage to motor neurons. It is shown to slow functional progression of disease by approximately 33%. This medication was previously offered only in IV form but is now available as a liquid. Side effects include bruising, problems with walking, and headache.

**Relyvrio** is a combination of two drugs that are thought to be neuroprotective by targeting mitochondrial dysfunction and endoplasmic reticulum stress. It slows loss of function by 25% and modestly extends survival. Side effects are abdominal pain, nausea, diarrhea, increased respiratory infections, increased saliva, and fatigue. It comes in powder that you mix with 8 oz of water. Please drink milk or eat honey immediately after the medication if you have concerns regarding taste. Avoid juice immediately after.

**Qalsody** is a drug in a new class of medications called antisense oligonucleotides, or ASOs. ASOs bind to the material that our body uses to make proteins called RNA. Qalsody, or tofersen, is designed to target the RNA that makes the protein SOD1, which can cause familial ALS. By preventing the SOD1 protein from being made, tofersen aims to slow down the damage to motor neurons and slow the disease progression. Tofersen does not affect other proteins or genes that may play a role in ALS. It must be given via a lumbar puncture (spinal tap). Initially it is given every two weeks for three doses. After that, the doses are given monthly for life.

Based on preliminary information from the studies, it is possible that the medication could cause inflammation in the spinal canal. This might result in back pain, headache, or nerve pain. As more people receive the medication, we will get a better understanding of how common side effects are.

## Genetic Testing

You may want to pursue genetic testing now that we have a treatment option for a type of familial ALS. Please discuss this with your provider so we can assist you with ordering this testing. This requires a visit to discuss the possible results prior to testing.

## Ordering Process & Costs

Some of these medications are considered “specialty medications,” meaning that they are usually higher cost and have to go through a prior authorization process and then be filled at a specialty pharmacy. The prior authorization process can take six to eight weeks. Your insurance may deny these medications due to various

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reasons. We will work to appeal denials, but they may not overturn this decision. Once approved by your insurance, you should get an understanding of your co-pay. If it is a large amount, please look into co-pay assistance programs below. These are for commercially insured patients.

## Discontinuing Medications

Discontinuing medications is usually due to quality-of-life factors, side effects, or cost. As discussed above, failure to notice changes on the drug does not mean that it is not working. Please discuss this with your provider.

## Co-Pay Assistance Programs

**JourneyMate - Radicava**
1 (844) 772-4548
Radicava.com/Patient/JourneyMate

**Amylyx Care Team (ACT) - Relyvrio**
1 (866) 318-2989
AmylyxCareTeam.com

**Qalsody**
1 (877) 725-7639

***Riluzole, Radicava, and Relyvrio can be given through your feeding tube.***