

Patient and Caregiver Guide to Infusion Therapy for Memory Disorders



To Our Patients and Caregivers,

We hope this guide provides you with much of the information you'll need for a smooth and comfortable infusion experience. If you have any additional questions or concerns, please don't hesitate to contact our clinic.

- Ochsner's Neurocognitive Clinic

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The Approval Process

What are infusion drugs for memory disorders?

Aducanumab (Aduhelm®), donanemab (Kisunla®), and lecanemab (Leqembi®), are known as an anti-amyloid medications. Anti-amyloid medications remove beta-amyloid, a protein that builds up to form plaques in the brain. Each of these drugs works to slow the advancement of a memory disorder.

Lecanemab and others are approved by the FDA to treat early Alzheimer's disease. They are also approved for people living with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's. They are intended to complement treatment you may already receive for Alzheimer's. If your test results show excess beta-amyloid in the brain, you may be a good candidate for anti-amyloid infusion therapy. Beta-amyloid is a protein linked to Alzheimer's disease.

Anti-amyloid medications are given as an infusion – through a vein – while you are at the hospital. Anti-amyloid infusion can give people with Alzheimer's more time to participate in daily life and live independently.

What is the approval process?

Before lecanemab treatment begins, you will need to complete specific steps to determine if you are eligible to receive it. You will also need prior insurance approval. Many insurance companies require you to contact them for approval before treatment begins. **This is particularly true for patients with Medicare coverage.**

Our dedicated nursing team will guide you through this process to ensure you and your loved ones complete the steps of the approval process.

The steps of the approval process

☐ Brain MRI within 1 Year

Before starting anti-amyloid treatment, you must have had a brain MRI (Magnetic Resonance Imaging) scan within the past year. This imaging test provides valuable information about the structure of the brain. It helps your care team see if any abnormalities are present and how they may have progressed.

□ APOE Genetic Testing

We know that the APOE (apolipoprotein E) gene affects how your body handles fats and cholesterol. Certain versions of this gene, like APOE4, can increase your risk for developing Alzheimer's. Testing for versions of the APOE gene is a crucial part of the approval process. A sample of your blood will be taken in the lab. This blood sample is evaluated to identify specific genetic variants associated with an increased risk of Alzheimer's disease. The results of these tests will help your provider determine if you are a good candidate for anti-amyloid treatment. They can also help you and your provider decide what treatment is best for you.

☐ Cognitive and Functional Testing

Healthcare professionals can measure how well a person can think, remember, and solve problems. This is called cognitive testing. They can also determine how well a person does daily tasks like cooking, dressing, or managing money. These are considered functional abilities. Tests of these two things are commonly referred to as cognitive and functional testing. They help doctors understand how a memory disorder might be affecting someone's brain and everyday life.

Medicare and other insurers may require recent cognitive and functional testing, typically completed within the past three to six months. These tests provide valuable information about your cognitive abilities and overall level of functioning. They help the care team understand how well you think and reason before treatment begins.

☐ Biomarker Testing

Biomarkers are specific substances in the body that indicate a disease may be present. Medicare often requires that a lumbar puncture (CSF analysis) or PET scan shows positive biomarkers for Alzheimer's disease before approving treatment. These tests will reveal if biomarkers such as beta-amyloid plaques, a hallmark of Alzheimer's, are present.

Once you've completed all the required tests and evaluations, our nursing team will enroll you in the Medicare lecanemab registry. This registry helps us coordinate your care and ensures we comply with the Medicare guidelines.

Then our nurse will connect you and your family with the Ochsner Pre-Service Department. The Pre-Service Department coordinates with your insurance company to ensure you are approved for treatment. They will request prior approval for anti-amyloid treatment on your behalf.



The prior approval process will take <u>AT LEAST 2 WEEKS</u>. Please be patient while we wait for a response from your insurance company.

Once we receive a response, our nurse will promptly let you know the outcome and any further steps required. Our goal is to streamline the approval process and ensure you get timely access to anti-amyloid treatment.

If you have any questions or concerns during this process, contact our nursing staff for assistance.

Caregivers play a vital role in the lecanemab treatment process. They are required to take an active role in supporting you during infusions. They will also help monitor your condition afterward.

Your care team will communicate with your caregivers regularly regarding the treatment process. If at any point you wish to change the person we communicate with, please contact a member of your care team.



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Durable Power of Attorney

We strongly encourage patients with memory deficits to establish a Durable Power of Attorney.

Importance of Power of Attorney

When you grant someone Power of Attorney, you give them legal authority to make healthcare decisions on your behalf, if necessary. This ensures that decisions regarding your care, including anti-amyloid treatment, can be made promptly and in your best interests. It only goes into effect if or when you're unable to make decisions for yourself.

A qualified Elder Law Attorney will give you and your loved ones personalized guidance to create a comprehensive Durable Power of Attorney. They will help ensure that your wishes are legally documented, and your interests are protected. Provide the attorney with a clear outline of your preferences and any specific instructions you want to be included.



The National Academy of Elder Law Attorneys has a list of lawyers registered with them. Visit www.naela.org/findlawyer to search for lawyers near your area.

If you already have a Durable Power of Attorney, please notify a member of your care team so that it can be uploaded to your electronic medical record.

You can also upload it to your medical record yourself via the patient portal.



- Sign in to the MyOchsner patient portal.
- From the Menu, look for the "Health Records" section.
- Choose the "Advance Care Planning" option and follow the prompts to upload your documents.

Ochsner's Power of Attorney

If you have not yet established Power of Attorney, our clinic will provide you with Ochsner's Power of Attorney paperwork. You must complete this paperwork before the first infusion. Our staff is available if you need help completing the form or have questions.

We require this to ensure you, your care team, and your loved ones can manage your care in the best way possible throughout the treatment process.

Ochsner's Power of Attorney is valid and true no matter where at Ochsner you receive care. (It may not be valid outside the Ochsner system.)

Ensuring Comprehensive Care

By establishing Power of Attorney, you are taking an important step to ensure comprehensive care and support for the duration of your treatment. Your designated caregiver will play a crucial role in advocating for your needs and coordinating with our clinic throughout the treatment process.

Starting Anti-Amyloid Infusion Treatment

Once you have been approved for anti-amyloid infusion, our nurse will contact you to

- Help schedule your first infusion appointment.
- Send you a consent form. When you sign this form, you give Ochsner doctors and nurses permission to provide treatment. This allows your care team to go ahead with infusion therapy. **You must sign it.**
- Order a baseline set of lab tests. These must be completed no more than 7 days before your first infusion.

Continuing Your Current Medications

It is crucial you continue taking all of your current medications as prescribed by your providers. Anti-amyloid infusion treatment is intended to complement your existing treatment plan. Do not stop taking any medications unless a member of your care team directs you to do so.

Preparing for Your Infusion Appointment

Arrival Time: Please arrive at least 15 minutes before your scheduled infusion appointment. This allows time for check-in and any necessary paperwork.

Hydration and Snacks: Drink plenty of water or non-caffeinated beverages before your infusion appointment. You may also bring a light snack. The infusion process can take several hours.

Comfortable Clothing: Wear loose, comfortable clothing that allows easy access to your arm for the infusion. Avoid wearing tight sleeves or multiple layers.

What to Expect at Your Infusion Appointment

- **1. Check-In:** When you arrive at the infusion center, you will check in at the reception desk. Our staff will assist you with the necessary paperwork and verify your information.
- **2. Vital Signs:** Before the infusion, a member of the care team will take your vital signs, such as blood pressure and heart rate. We measure these to ensure your safety during the procedure.
- **3. Infusion Setup:** You will sit in a comfortable chair in the infusion center. A trained healthcare professional will prepare and administer the infusion through an intravenous (IV) line.
- **4. Duration:** The infusion process typically takes about two hours. You may want to bring activities such as a book, magazine, or electronic device to help pass the time.
- 5. Monitoring: Your infusion nurse will monitor you throughout the infusion to ensure your well-being and address any concerns or questions you may have.



Post-Infusion Care

Observation Period: After the infusion is complete, a member of the care team will monitor you for a short period. This is to ensure you don't have any negative reactions immediately after the infusion.

Discharge: Once the observation period is complete and you are feeling well, you will be discharged. A member of the Ochsner staff will provide any necessary post-infusion instructions.

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Continuity of Care and Follow-Up

The Ochsner Neurology Clinic is here to provide ongoing care and support throughout your journey with anti-amyloid infusions.

Follow-up appointments

To ensure your care continues on the right schedule and in the right way, you will see a member of your care team at key intervals along your treatment plan.

• 3 Months - Virtual Follow-Up

Appointments at the 3-month mark will allow us to monitor your progress and make any necessary adjustments to your treatment plan.

6 Months - In-Person Follow-Up

Regular check-ins at the 6-month mark are essential for evaluating the long-term effectiveness of anti-amyloid infusion and ensuring your well-being.

12 Months - Follow-Up

A comprehensive follow-up at the 12-month mark enables your care team to assess the overall impact of the infusions on your condition. We'll also discuss any future course of treatment.

Labs

To ensure your continued safety and well-being, we will schedule lab work every 3 months.

MRIs

To ensure your safety and to comply with Medicare guidelines, we will schedule MRIs at the following intervals.

- Before your 5th infusion
- Before your 7th infusion
- Before your 14th infusion

Importance of Caregiver Involvement

It is absolutely necessary that each individual undergoing anti-amyloid infusions has a designated caregiver. This person will stay with you throughout the process. They play a crucial role.

Monitoring Symptoms and Condition

Your caregiver will observe and note any changes in symptoms or unexpected reactions during and after the infusion. This information is valuable for your care team to ensure your safety. We will use it to adjust the treatment plan if necessary.

Assisting with Communication

Your caregiver serves as a vital link between you and our clinic. They can help articulate your concerns, report any side effects, and provide essential details that contribute to your personalized care.

Attending Appointments

We encourage your caregiver to physically attend appointments with you. This ensures that they are familiar with the treatment process and can actively participate in discussions about your care.

We understand the importance of a strong support system. Having someone you trust involved is fundamental to your well-being. If you have any challenges in arranging for a caregiver, please contact our clinic and we will work with you to find a suitable solution.

Safety Concerns and Monitoring Reactions to Anti-Amyloid Medication

Your safety and well-being are our top priorities throughout the treatment process. We must all be vigilant to watch for any potential symptoms or reactions.

Monitoring for Symptoms

During and after your infusions, it is important for you and your caregiver to monitor for symptoms or reactions that may occur. If you notice any of these symptoms, contact the clinic immediately.

- Headaches
- Nausea
- Unusual fatigue or lack of energy
- Feeling lightheaded or unsteady when standing or walking
- Allergic reactions such as rash, itching, swelling of the face or lips, or difficulty breathing



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Stay Connected

We encourage you to stay connected with our clinic for any concerns or updates. The best way to reach us is via the MyOchsner portal. If you cannot reach us that way, call 504-842-3980.

Use MyOchsner, our secure patient portal, to communicate with our clinic, update us on your progress, and ask questions.

If you haven't already registered for the portal, please ask at the front desk. Someone will help you set up a MyOchsner account and help you learn to use it.



MyOchsner should not be used for urgent medical needs.

Reporting Symptoms



If you experience any symptoms or reactions, please contact our clinic immediately at 504-842-3980. When calling, state, "I am an anti-amyloid patient, and I am experiencing [describe symptoms]." This will alert our staff to prioritize your message.

Once we receive your message, someone will promptly review it and ensure that it is directed to your provider's team for further evaluation. A member of our team will then contact you as soon as possible to provide guidance and advise on the next steps.

Emergency Situations

In the event of a medical emergency or severe reaction, call 911 or go to your nearest emergency room. **Be sure to tell the emergency providers that you are on anti-amyloid treatment and cannot receive TPA (tissue plasminogen activator) due to the risk of bleeding.** Emergency room personnel may reach out to our office with any additional questions.

After any emergency room visit, please let us know as soon as possible. That way we can follow up with you for any ongoing support you need.



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