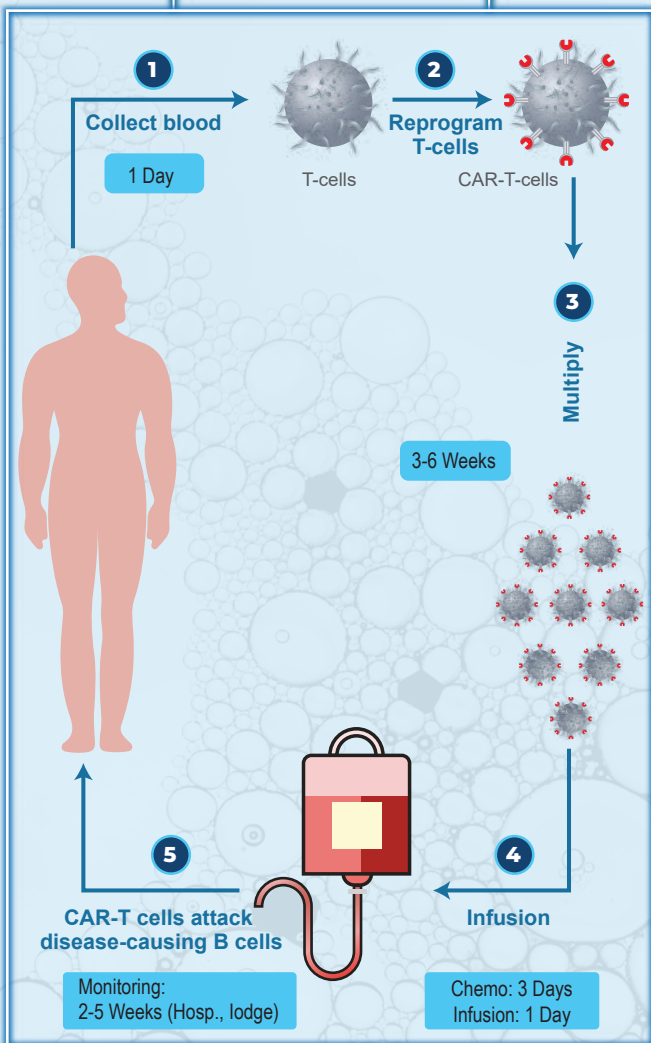


CAR T CELL THERAPY



Myositis
Clinical
Trial
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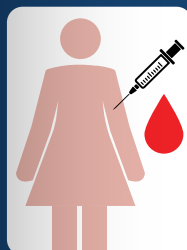
What is CAR T Cell Therapy?



CAR T cell therapy is an advanced form of immunotherapy that is currently approved for certain conditions and is now being studied in clinical trials in patients with autoimmune diseases such as myositis, who have not responded to other treatments. This therapy often involves modifying a patient's T cells—a type of immune cell—to recognize and attack disease-causing cells associated with cancer or autoimmune conditions. Your rheumatologist can provide you with more information, including the inclusion criteria for this treatment. CAR T cell therapy may put your disease in remission and reduce the need for long-term medications.



Doctors collect T cells from the patient's blood and then carefully engineer them by adding a new gene. This gene adds a special receptor to the surface of T cells called a **chimeric antigen receptor** (CAR). This receptor can be designed specifically to bind to proteins found on the surface of B cells, including disease-causing B cells.



Once the T cells are modified to express this receptor, they are expanded in the laboratory—multiplied into the billions. Several weeks later, they are infused back into the patient. These can now identify and kill all B cells, including disease causing B cells, leading to a targeted attack of the cells that may be causing the disease and symptoms.

CAR T CELL THERAPY FOR MYOSITIS Patients FAQs



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A Collecting T Cells From Patients

Q: How are the T cells collected and grown?

A: T cells are collected from your blood in a process called apheresis. Blood is drawn through a PICC line in your arm, which makes it easier to draw blood over several hours. A machine separates out the T cells, and the rest of your blood is returned to you. Those T cells are then genetically modified and multiplied in a specialized lab, a step that usually takes about 3–6 weeks before they're ready to be infused back into you. If you receive 'off-the-shelf' CAR T cells, pre-made from a healthy donor, you can skip both the collection procedure and the waiting period for cell manufacturing.

Q: What is pre-conditioning?

A: A short course of chemotherapy (fludarabine & cyclophosphamide), usually given over 3 days before your CAR T cells are infused. This is called pre-conditioning, and it helps to ensure that the CAR T cells can grow and multiply once they are infused back in your body. You may experience mild to moderate side effects (fatigue, nausea, appetite loss), if those are significant, the infusion date may be delayed by a few days.

B Infusion And Post-infusion Monitoring

Q: What can I expect during the CAR T cell infusion?

A: The infusion process is often quick. However, every institution has its own protocol for how long the infusion takes.

Q: Are there immediate side effects during the infusion?

A: You might experience a slight fever or chills. Medical staff will monitor you closely throughout the infusion for any reaction. In rare cases, patients may report a taste of creamed corn during the infusion due to the preservative used in the cell storage.

C Monitoring Post-infusion

Q: What post-infusion care is required after CAR T cell therapy and what are the possible complications?

A: Post-infusion care includes regular monitoring of your blood counts, overall health, and managing side effects. Most patients stay in the hospital 2–5 weeks for close observation. Possible complications include:

- Cytokine Release Syndrome (CRS): More common. (30-50%) Can range from mild (fever, chills) to severe (rapid heartbeat, low blood pressure) and may extend hospital stays.
- Immune Effector Cell-Associated Neurotoxicity Syndrome (ICANS): Can cause confusion, trouble speaking, or in severe cases, seizures. Your team will check you daily to detect and manage symptoms.
- Local Immune Effector Cell-Associated Toxicity Syndrome (LICATS): Common, mild inflammation in previously affected areas, usually resolving within about 11 days without long-term effects.

Q: What is an approximate timeline for a CAR T cell trial from beginning to end?

A: The CAR T cell therapy process takes about 6–12 weeks from start to finish (excluding long-term follow-up). "Off-the-shelf" CAR T trials may be shorter. Hospital stays typically last 2–5 weeks.

Q: How long does it take to recover after CAR T therapy?

A: Recovery times vary—some feel better in weeks, others take months. Fatigue is common.

TIPS from CAR T Patients

- "A strong support system is almost mandatory—don't try to go it alone. You need your loved ones nearby"
- "Avoid feelings of isolation. Ask about what therapies (art, music, counseling) the hospital offers to cope with isolation."
- "Keep a record of travel and meal costs—many trials will reimburse you quickly."

D Navigating CAR T Cell Therapy

Q: Will I need to stay near the hospital after the procedure?

A: Yes, most patients must stay within a certain distance from the hospital for a period ranging from a few weeks to a month after the infusion to allow for close monitoring and immediate care if needed.

Q: Can I return to normal activities after CAR T cell therapy?

A: While many patients do return to normal activities, the timeline varies. Following your healthcare provider's advice on activity levels and restrictions is essential. There will be a long-term follow-up (2+ years in many trials).

Q: What financial or accommodation support is available during the Clinical trial?

A: Many trials provide explicit reimbursements for travel, lodging, and meals—sometimes via a prepaid debit card or fast-track reimbursement. Reimbursements for caregiver expenses are also included, please confirm. Keep records of receipts and consult with your assigned research nurse or social worker about timing and documentation requirements.

Q: What role will my caregiver play?

A: CAR T cell therapy is a complex process in which your caregiver and family will play a significant role in every aspect of the therapy journey – medical, emotional, logistical, and financial. Patients are often too weak to handle basic tasks alone in the initial weeks. Make a comprehensive plan along with your caregiver considering the times in the hospital and nearby and how both of you will handle staying away from home.

Q: Do hospitals offer any type of patient counseling?

A: Hospitals often offer counseling, art therapy, music therapy, or social work services to help cope with stress. Ask your treatment center if they provide or can refer you to support services (e.g., counseling, massage therapy, child life specialists) for emotional well-being, especially if you must travel out of state.