

Understanding and Navigating Barriers to CAR T-Cell Therapy



A Fact Sheet for Patients and Caregivers



CAR (chimeric antigen receptor) T-cell therapy is type of cancer treatment that uses a patient's own immune cells — called T-cells — to find and fight cancer. CAR T-cell therapy is a type of cancer treatment called immunotherapy. Collecting and changing your T-cells is a complex process, and it can cause very serious side effects. Currently, most of the patients treated with CAR T-cell therapy have been people with blood cancers. New CAR T-cell therapies and new ways to use approved therapies are being studied in clinical trials.

While this treatment offers hope, it also comes with emotional, financial, logistical, and caregiving demands. This fact sheet outlines the most common barriers, along with practical solutions to help patients, caregivers, and their loved ones navigate CAR T care with confidence.



Visit CSC's webpage on CAR T for more information:
www.CancerSupportCommunity.org/Car-T-Cell-Therapy



PRACTICAL & LOGISTICAL BARRIERS



Travel and lodging needs. Many treatment centers that offer CAR T-cell therapy are located in major cities or academic hospitals. Families may often need to travel long distances, remain near the treatment center for weeks, and pay for lodging and meal costs.

What you can do:

- **Use navigation support:** Patient navigators help families find a place to stay, explore travel assistance, and connect with community resources. Call Cancer Support Community's CAR T Helpline at 844-792-6517.
- **Ask your CAR T center about housing partnerships:** Many hospitals have discounted housing, partner hotels, or guest programs for patients.
- **Plan early:** Begin arranging travel and lodging as soon as you receive your referral to avoid last-minute stress.
- **Ask about telehealth options:** Some treatment visits may be available remotely.
- **Lean on your support team:** Ask friends or family to help research or book travel to reduce additional stress on your caregiver.

Managing multiple appointments and complex scheduling.

CAR T involves many steps — evaluations, blood tests, cell collection (apheresis), education visits, infusion, and frequent follow-up appointments. These appointments can be spread over several weeks to months.

What you can do:

- **Create a shared calendar:** Involve caregivers and supporters so everyone knows the schedule.
- **Ask appointment coordinators for “bundled scheduling”:** Many treatment teams can group appointments to reduce extra trips.
- **Coordinate with your local oncologist:** Some labs and follow-up visits may be done closer to home. This coordination is usually done by the CAR T team; however, you may wish to ask if there are other labs/appointments that still need to be scheduled with your local care team.
- **Assign one caregiver as the “logistics captain”:** While one caregiver can take the lead on logistics, other tasks can and should be shared to avoid caregiver burnout.



Working with a large care team. CAR T patients often work with oncologists, nurses, pharmacists, social workers, and navigators. Knowing who to call — and when — can be confusing.

What you can do:

- **Confirm communication channels:** Ask your care team who to contact for different types of questions or concerns.
- **Share contact lists with caregivers:** This ensures everyone knows how to get help quickly.
- **Ask your care team about a single point of contact:** Some centers offer nurse navigators who coordinate your care.



FINANCIAL BARRIERS



High out-of-pocket costs for non-medical needs.

Even when insurance covers CAR T itself, families may still face costs for travel, lodging, transportation, food, and unpaid time away from work.

What you can do:

- **Connect with patient and financial navigators:** Navigators help families access financial support programs, including help for lodging, travel, and medication costs. Call Cancer Support Community's CAR T Helpline at 844-792-6517.
- **Request a financial counselor at your treatment center:** They can estimate costs and help with payment plans or charity care.
- **Look into nonprofit travel support:** Several national programs offer reduced-cost or free airfare and lodging for cancer treatment.
- **Plan early for hidden expenses:** Budget for meals, gas, parking, and other small costs that can add up.

Learn how to talk about the financial side of cancer and where to go for help.
www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment



Employment and income disruption. It is common for CAR T families to face challenges with FMLA (protection for medical leave), disability paperwork, and balancing work responsibilities while caregiving or undergoing treatment. Patients may need weeks off, and caregivers may need to be available full-time during monitoring.

What you can do:

- **Explore work accommodations:** Patient navigators help identify options such as FMLA, short-term disability, and workplace protections. Call Cancer Support Community's CAR T Helpline at 844-792-6517.
- **Talk early with employers:** Provide them with estimated treatment timelines and ask if remote work, flexible hours, or intermittent leave are possible.
- **Share tasks with your support network:** Involve friends and family in logistical support to reduce time away from work.

Learn more about employment and cancer here:

www.CancerSupportCommunity.org/Employment-Cancer



EMOTIONAL & PSYCHOSOCIAL BARRIERS

Fear, uncertainty, and emotional stress. CAR T is a newer treatment, and patients may worry about whether it will work or what side effects to expect. Also, the CAR T process includes many steps, and misunderstanding what comes next can worsen stress.

What you can do:

- **Speak to a social worker or mental health specialist:** Licensed oncology social workers and mental health professionals can help families manage anxiety and fear. Visit www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns.
- **Practice self-care daily:** Even short activities like breathing exercises, journaling, or walking can reduce stress.
- **Find peer support:** Connecting with others going through CAR T can help you feel less alone and remind you that your feelings are normal.
- **Ask providers to explain things in plain language:** You can also ask for printed information and instructions. Understanding the process reduces fear.
- **Use a step-by-step planning tool:** CSC's CAR T guide helps break big tasks into manageable steps and reduce the emotional burden of uncertainty: www.CancerSupportCommunity.org/Car-T-Patient-Caregiver-Guide.
- **Bring a caregiver to appointments:** Sharing responsibility between you and your caregivers can help reduce stress.

Caregiver stress and burnout. Caregivers are often responsible for coordinating logistics, providing emotional support, monitoring symptoms, and managing household duties.

What caregivers can do:

- **Lean on your support network:** Friends and family can help with tasks like driving, errands, and keeping loved ones updated. Don't be afraid to ask — people often want to help.
- **Set boundaries and rest:** Caregivers may feel overwhelm and distress during this process. It is important for them to also take time to rest and recharge, in any way that works best for them.
- **Communicate openly with the care team:** Share concerns early so the team can help.



Caregivers need support, too. Find programs and services that can help:
www.CancerSupportCommunity.org/Caregivers



SIDE EFFECT MONITORING & SAFETY BARRIERS

Need for constant monitoring after infusion. CAR T can cause serious side effects like cytokine release syndrome (CRS) or neurological symptoms. Patients often cannot drive, and caregivers must remain available around the clock during the early weeks.

What you can do:

- **Share with your entire caregiving team:** Make sure everyone knows the signs that require urgent medical attention.
- **Keep a symptom diary:** Work with your caregiver to track changes in behavior, temperature, and physical symptoms.
- **Keep emergency contacts accessible:** Keep a list of day, night, and weekend numbers.
- **Plan for backup caregivers:** If one caregiver needs rest, another can step in. These loved ones can also help observe and record symptoms.
- **Stay near the treatment center:** This ensures quick access to medical support if symptoms arise.
- **Call the team early rather than waiting:** Treatment centers expect frequent communication.



CAR T-cell therapy can be life-changing, but the emotional, logistical, financial, and caregiving challenges can feel overwhelming. With the right support — especially navigation, education, and emotional resources — **patients and caregivers can approach the CAR T process with confidence and clarity.**



RESOURCES

CAR T-CELL THERAPY RESOURCES

Cancer Support Community

CSC-867-5309 (or outside the U.S., toll-free 888-793-9355) | www.CancerSupportCommunity.org/Car-T-Cell-Therapy

Cancer Support Community CAR T Navigation

844-792-6517

American Cancer Society - CAR T-Cell Therapy

800-227-2345
www.Cancer.org/Cancer/Managing-Cancer/Treatment-Types/Immunotherapy/CAR-T-cell.html

BMT InfoNet

BMTInfoNet.org/Directory-Car-T-Cell-Therapy-Centers

Bone Marrow & Cancer Foundation

800-365-1336 | www.BoneMarrow.org

Blood Cancer United

800-955-4572 | BloodCancerUnited.org

The IMF (International Myeloma Foundation)

800-452 CURE (2873) (or outside the U.S./Canada: 818-487-7455
Myeloma.org



Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline at CSC-867-5309 (or outside of the U.S., toll-free 888-793-9355), available in 200 languages.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more
www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.org**.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at **www.CancerSupportCommunity.org/Become-Advocate**.

This publication is available to download and print yourself at
www.CancerSupportCommunity.org/CAR-T-cell-Therapy.

For print copies of this publication or other information about coping with cancer, visit
Orders.CancerSupportCommunity.org.

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CAR T-cell Therapy Program Partner:



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