

Planning ahead for CAR T

A guide for patients and caregivers



What is this guide?

This guide is created for:

- **patients** who are familiar with CAR T-cell therapy (CAR T), and are seriously considering or planning for CAR T as a treatment option
- **caregivers** to support patients in their discussions as they plan for CAR T



There are many steps in the CAR T process, which can take time to organize and prepare for. This guide will walk you through what you can expect, and help you identify topics you may want to discuss with your caregiver(s) or healthcare team to help you plan ahead.

Use this guide to:

- review the steps of the CAR T treatment process
- learn about the different people or organizations that can help you
- identify your concerns or types of support that you may need
- talk with your healthcare team so they can help you address concerns, and provide information about supports or services available



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What is the CAR T treatment process like?

Review the steps of the CAR T treatment process to get an idea of what to expect and when you may need support. While these steps are common, everyone's experience may look different.

Before treatment



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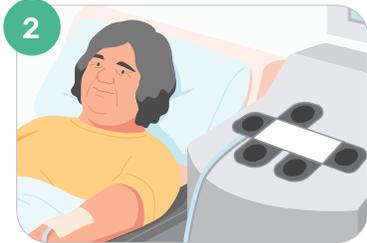
Attending your CAR T consultation

In the US, CAR T is only offered at certain medical centers. You may need to travel to a center and meet the treatment team. This consultation will include various tests and checks to make sure CAR T is right for you, and may involve looking into your insurance coverage.

Average time: About 1 day, but timing may vary

Where: CAR T medical center

During treatment



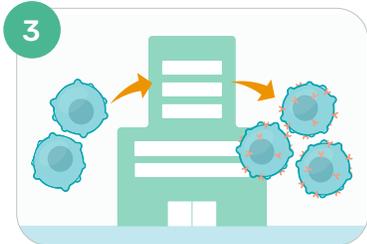
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Collecting your T cells (apheresis or leukapheresis)

At the CAR T medical center or apheresis center, your T cells will be collected from your blood.

Average time: 1 day (the procedure can take about 4 hours)

Where: CAR T medical center or apheresis center



3

Waiting for your CAR T cells

You'll wait while your CAR T cells are made at a specialized facility.

Average time: Generally from 2 to 6 weeks (but can be longer)

Where: At home or near the CAR T medical center



4

Preparing your body to receive your CAR T cells

You'll receive low dose chemotherapy to prepare your body for CAR T. This process can start 2 to 14 days before your CAR T infusion.

Average time: Low dose chemo each day for 3 days, followed by 1-2 days of rest. Timing may vary

Where: Low dose chemo at a CAR T outpatient infusion clinic, or at the CAR T medical center; rest at home



5

Receiving your CAR T cells and close monitoring

You'll receive your CAR T infusion, and your healthcare team will watch for and manage any side effects.

Average time: 1 day for CAR T infusion. There will be at least 2 weeks of close monitoring after infusion, including daily monitoring during the first week.

Where: Infusion at the CAR T medical center (may be given outpatient if available at the center and if you're eligible). Monitoring at a healthcare facility.

After treatment



6

Recovering at home

Your follow-up appointments may be at the CAR T medical center, at a healthcare facility, or you may go back to your local cancer clinic. You and your caregiver will continue watching out for symptoms. You will continue to rely on your caregiver(s) as you get back to your daily activities.

Average time: Varies by patient

Where: At home

For more information on the steps of CAR T, visit [LetsChatCART.com/treatment-process](https://letschatcart.com/treatment-process)

What are the responsibilities of a CAR T caregiver?

Caregivers are an important part of the CAR T treatment process. You need a caregiver in order to receive CAR T. Caregivers are often a partner or family member, but they can also be friends, members of your community, roommates, or as needed, someone you hire. Caregiving duties can be shared across more than one person—with primary and secondary caregivers.

The list below is a starting point for caregiving responsibilities to consider. Discuss where and when you might need additional help, and who in your support network can help. Talk to your healthcare team if you need help finding a suitable caregiver.

During treatment

A key role for caregivers is to watch out for side effects after the CAR T infusion, especially in between check-ins with the healthcare team. Some side effects may be hard for you to recognize, and you'll need a caregiver after the CAR T infusion.

The treatment team will give detailed instructions on what to look for and what to do. They will be monitoring for side effects as well, and managing them appropriately.



Other caregiving responsibilities during this time may include:

- driving or organizing travel, and accompanying you to appointments
- finding a place to stay near the CAR T medical center (if you do not live nearby)
- staying with you near a healthcare facility for at least 2 weeks

After treatment

Caregiving responsibilities may include:

- continuing to monitor for side effects
- driving or arranging transportation (after treatment, you should avoid driving for at least 2 weeks as you'll often deal with fatigue)



Other common caregiving responsibilities may include:

- medication management
- asking questions alongside you and taking notes
- helping with personal care and hygiene
- day-to-day household tasks (e.g., groceries, cooking)

For more information on caregiver responsibilities and support available, visit LetsChatCART.com/caregiver-support

Who else can provide support?

Since CAR T involves many different steps, you may need support in ways you haven't needed before. There are people and organizations who can help you such as:

Nurse navigator (clinical nurse coordinator)

A nurse navigator is often present throughout the CAR T treatment process. They keep in touch with you between appointments, and can help with:

- scheduling appointments
- reviewing what to expect
- providing assistance with identifying a caregiver/caregivers
- connecting you with additional support
- transitioning back to your primary oncologist after you've been discharged

Social worker

A social worker may be able to help you solve challenges in your day-to-day life, such as:

- helping you manage stress that comes with having cancer and receiving treatment
- finding a place to stay near the medical center
- finding and arranging for transportation
- navigating benefits (e.g., disability or family leave)
- finding financial assistance

Advocacy and support groups

Many advocacy groups have resources and people whose role is to help you find the support you need—you don't have to figure it out on your own. See the next page for a starting point of groups you can reach out to.

Friends, family, and community

Friends, family, and members of your community can help take on caregiving responsibilities, help with practical tasks (like making food, caring for a pet, checking on your house), provide emotional support (like talking on the phone), and more.

CAR T manufacturer

Manufacturers often have programs, services, and people who can help you identify support. Talk to your nurse navigator or social worker to find out more details about specific support that might be available to you.

Helpful contacts

My nurse navigator(s) and social worker(s)

You can use this guide in discussions with your nurse navigator(s) and social worker(s) as you plan ahead for CAR T. They may be able to help you address non-medical concerns and questions and provide information about support or services available.

Nurse navigator(s)

Name
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Email
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Phone
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Name
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Email
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Phone
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Social worker(s)

Name
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Email
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Phone
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Name
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Email
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Phone
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Advocacy and support groups

Below is a starting point of groups you can reach out to. Some offer support in multiple languages. Visit the links to learn more about the services and programs offered.

Cancer Support Community: CAR T Cell Therapy Navigation

<https://www.cancersupportcommunity.org/car-t-navigation-referral>

1-888-793-9355

Blood Cancer United: Information specialists

<https://bloodcancerunited.org/resources/patients/information-specialists>

1-800-955-4572

Lymphoma Research Foundation: Lymphoma Helpline

<https://www.lymphoma.org/resources/supportservices/>

1-800-500-9976

Resources may include referrals to independent third-party nonprofit patient assistance programs. These programs are not operated or controlled by Kite and Kite does not endorse any program or third-party organization. Nonprofit patient assistance program eligibility requirements may vary and are established solely by each independent organization.

Remember, you can talk to anyone on your healthcare team for more information or help.

What types of support should I consider?

CAR T has some unique considerations that may be different from other treatments you're familiar with. The list below is a starting point. Read about each area of support, and check off items that you may need help with or want to know more about. Then, bring it to your healthcare team for discussion.



Caregiving

Caregivers are an important part of the CAR T treatment process. Plan ahead to find one or more caregivers that can support you throughout treatment. Think about whether you need help with:

- finding a suitable caregiver(s)
- hiring a caregiver(s), as needed
- understanding the responsibilities of a CAR T caregiver
- talking to a potential caregiver about responsibilities throughout the treatment process
- caregiver(s) being able to take time off work
- finding support or help for my caregiver(s)

My caregiver(s):

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Financial

Understanding all the costs and what is covered by your insurance can be overwhelming, but there are people on your healthcare team, like nurse navigators or social workers, that can help you figure things out. Financial support can also come in many forms, like grants, coupons and vouchers, reimbursements, or volunteers. Think about whether you need help with:

- understanding the cost of treatment and additional medical costs (e.g., hospital stays, test and procedures, medications)
- understanding costs like travel and lodging (e.g., car rental, gas, hotel, etc.)
- understanding whether your insurance provides any coverage or support
- applying for financial support programs you may be eligible for
- managing possible income loss (for yourself or your caregiver) due to being away or taking time off work
- identifying and finding support for other costs like caregiving, childcare, cleaners, etc.



Practical

You and your caregiver(s) may want help throughout the treatment process – like caring for your family, your home, transportation, and more. Below is a starting point of tasks to consider. Knowing specifically what you need help with can make asking easier.

Consider using a calendar to help stay organized with tasks, appointments, and who can help. Your healthcare team may have a calendar for you to use.

Think about whether you need help with...

Who from your support network might be able to help?

<input type="checkbox"/>	shopping for groceries	
<input type="checkbox"/>	organizing or preparing meals	
<input type="checkbox"/>	managing household chores (e.g., laundry, cleaning, yard work)	
<input type="checkbox"/>	booking travel and lodging	
<input type="checkbox"/>	packing for travel	
<input type="checkbox"/>	traveling/driving to appointments	
<input type="checkbox"/>	picking up your mail	
<input type="checkbox"/>	checking on your home while you're away	
<input type="checkbox"/>	helping with family care (e.g., children or elders)	
<input type="checkbox"/>	looking after your pets	
<input type="checkbox"/>	paying your bills	
<input type="checkbox"/>	<i>other...</i>	
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Educational

Your healthcare team is your main resource when it comes to understanding your treatment. There are also programs that connect you with information specialists, or to patients and caregivers with cancer experience. Think about whether you need help with:

- learning more about CAR T
- talking to other patients or caregivers about their experiences
- connecting with advocacy organizations—they often provide educational resources and seminars
- accessing translation services



Mental or emotional health

You may already have ways to cope with feelings on your own. It can also be helpful to ask for support from a professional. You don't have to go through this experience by yourself. Think about whether you need help with:

- finding counseling or professional help from a therapist or social worker
- finding a peer-to-peer support group
- connecting with an advocacy group



Physical well-being

You may want help adjusting habits or setting new ones to stay physically well as you go through treatment. Think about whether you need help with:

- nutrition
- healthy sleep habits
- exercise and recreation
- physical therapy



What else is on your mind? What are your top concerns?

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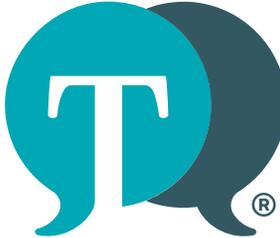
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You may use this space to write notes from discussions with your healthcare team.



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Let's Chat CAR T



For more information on CAR T, visit LetsChatCART.com

