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ABOUT CANCER
A PROGRAM OF THE CANCER SUPPORT COMMUNITY

CAR T Patient & Caregiver Guide

A step-by-step guide for adult CAR T cell therapy patients and their caregivers from referral through treatment and follow-up.

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GILDA'S CLUB

Contact Information

My Name ______________________________

My mobile number *(or other way to contact you in case you leave this behind)* _____

____

My Treatment Team Emergency Contact:

- Date ______________________________

The person to call on my treatment team if I have a problem is ______________ .

The phone number during office hours is ______________________ .

If it is an evening or on a weekend, contact ______________________

at this number ______________________________ .

Your emergency contact person may change at different steps in your treatment. Update your new contact information here:

- Date ______________________________

The person to call on my treatment team if I have a problem is ______________ .

The phone number during office hours is ______________________ .

If it is an evening or on a weekend, contact ______________________

at this number ______________________________ .

- Date ______________________________

The person to call on my treatment team if I have a problem is ______________ .

The phone number during office hours is ______________________ .

If it is an evening or on a weekend, contact ______________________

at this number ______________________________ .

Keep the rest of your CAR T team contacts in the **My Treatment Team Contacts** section at the back of this binder, starting on page 121, so they are all in one place.

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How to Use This Guide

This guide is designed for adult cancer patients and their caregivers who have been referred to a cancer center that offers CAR T cell therapy. CAR T cell therapy is a new type of cancer treatment that may be a good option for some patients. This guide provides step-by-step information from referral to treatment to the follow-up process. Included are questions for your treatment team, planning checklists, tips for coping, and a sample timeline.

Many people travel from out of town to receive this therapy. There are several steps in the CAR T therapy process. Each step is different and requires patients to prepare in different ways. Because of this, patients and caregivers need to deal with everything involved in this week's appointments, while at the same time plan for next month's appointments. We hope this guide makes your CAR T journey easier to manage.

If you and the CAR T team determine CAR T is right for you, this guide can help you and your caregiver work with your doctors to plan and prepare for all the steps in the CAR T process. You can keep this guide with you and refer to it regularly to help you plan ahead, advocate for yourself, and map out what your path looks like.

This guide is broken up into 3 sections with the first 2 sections building on each other.

SECTION 1:

Gives you basic information about CAR T therapy including how to get started, clinical trials, requirements for caregivers, and possible costs.

SECTION 2:

Walks you through the CAR T therapy process, from your referral to the CAR T program to treatment and follow-up after treatment. It includes color-coded checklists to help you think through the right questions to ask, what to expect, and how to develop a logistics plan.

SECTION 3:

Provides resources to help you keep track of appointments, important contact information, medications, and tests results. Use this section to take notes before, during and after appointments. You can always download and print additional pages as you need them from **www.CancerSupportCommunity.org/CART**.

You do not have to go through this alone. Although this guide talks about what "you" need to do, we hope a larger group of people will help you through the process. So "you" really means you and your primary caregiver(s), as well as members of your CAR T team and larger support network. Ideally, your larger support network can help you with the many different parts of the planning and therapy process.

You and your primary caregiver should accept all the help and support you can. This support network may include members of your CAR T team such as your oncology social worker, patient navigator, CAR T nurse, and others. Friends and family can help you with many of your planning and logistic tasks, even if they are not able to be in-person caregivers during your treatment. Tasks may include helping you find lodging or transportation if you are traveling for treatment, driving you during the period you are home but unable to drive, or keeping your larger support network updated with your treatment and results.

Laurie, CAR T survivor, with her son, Gus, on her CAR T infusion day.

Section 1

CAR T Cell Therapy Basics

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What is CAR T Cell Therapy?

What Does CAR T Stand For?

CAR T cell therapy, or Chimeric Antigen Receptor T cell therapy, is one way to use the body's natural defenses to fight cancer. It is called CAR T cell therapy because a lab-made protein, called a chimeric antigen receptor (CAR), is added to the patient's own T cells, which are a type of white blood cell found in your immune system. The CAR protein helps T cells target cancer cells to be killed and helps train your immune system to attack the cancer.

> "We have figured out a way for your T cells to be modified to learn how to recognize cancer cells in the same way that they do a virus and bacteria. We are giving these cells the eyes they need to be able to see the cancer cells."
>
> —Lizzy Weber, RN, Cellular Therapy Coordinator, Penn Medicine

CAR T STANDS FOR:

C

CHIMERIC

The CAR protein is called “chimeric” (pronounced ky-MEER-ic) because scientists add this protein to your T cells to get it to better recognize cancer cells. In Greek mythology, a “chimera” was an animal with a lion’s head, a goat’s body, and a serpent’s tail. So “chimeric” means something has parts of different origins. In biology, a chimera is an organism that has a mixture of genetically different cells.

A

ANTIGEN

Antigens are proteins on the cancer cell that help T cells recognize the cancer cell as something to attack. In general, the immune system works by finding cells with abnormal antigens and attacking them.

R

RECEPTOR

The CAR protein, which acts like a cancer-cell tracking device, is added to the altered T cell. With the CAR protein added, your T cells become CAR T cells. They can more easily find and destroy cancer cells. The CAR acts as a receptor. These receptors then search for the matching antigen on a cancer cell so the T cell can destroy it.

T

T CELL

These white blood cells are a normal part of your immune system. They roam throughout the body to seek out and attack viruses, bacteria, and abnormal cells like cancer. In CAR T cell therapy, these T cells are altered to better find and attack cancer cells.

What is CAR T Cell Therapy?

CAR T cell therapy, or CAR T, is a type of cancer treatment that helps your immune system see and kill cancer cells. This type of treatment is called immunotherapy. The U.S. Food and Drug Administration (FDA) approved the first CAR T therapy in 2017. CAR T is an approved treatment option for patients who have multiple myeloma and certain types of leukemia and lymphoma. CAR T is not a first line treatment. Patients who receive CAR T have usually had two or more previously unsuccessful treatments. To learn more about approved CAR T drugs, visit **www.CancerSupportCommunity.org/CART**.

At first, CAR T treatments were only available at a few cancer centers. Now more than 150 cancer centers in the U.S. offer CAR T cell therapy. Your oncologist may work at a cancer center that has a CAR T program. If not, they may refer you to a program at another cancer center. This center may be near you or in another city or state. To get CAR T, you may need to be away from home for several months at a time.

You may have read or heard that all people who get CAR T are "cured." This is not true. For some people, the treatment works very well. Some patients can enter remission with CAR T therapy. Remission means that the signs and symptoms of cancer are gone, and the cancer has disappeared from blood or bone marrow. Some of these patients may ultimately be cured, but unfortunately some do later suffer relapse. Alternatively, some do not respond fully and look for other treatment options. For other patients, it doesn't work at all. To see if this treatment is right for you, your primary oncologist will refer you to a treatment team that offers CAR T. This guide can help you and your caregivers at each step of the CAR T cell therapy process.

> "I think what CAR T gives so many people is hope—the hope that maybe this will work. After exhausting all possible treatment options, maybe using my own immune system to fight the cancer will work."
>
> —Kristin, CAR T patient

MORE WORDS TO KNOW

APHERESIS

A procedure that allows white blood cells to be removed from the bloodstream, while the rest of the blood (red blood cells, platelets, plasma) is returned to the patient.

BRIDGING THERAPY

Treatment you receive between apheresis and infusion of CAR T cells. Bridging therapy tries to keep the cancer under control so you remain healthy enough to get your CAR T infusion. Most often, the therapy is chemotherapy, but radiation is sometimes used. Bridging therapy is not needed for everyone.

CAR

A protein that can help T cells, a type of white blood cell, target cancer cells to be killed.

CAR T CELLS

After your T cells are altered to add the CAR protein to them, the altered cells are called CAR T cells.

CONDITIONING CHEMOTHERAPY

A low dose of chemo given a few days before CAR T infusion to make room for your new CAR T cells.

CYTOKINE RELEASE SYNDROME (CRS)

A side effect of immunotherapy that can cause a wide range of symptoms, often starting with a fever. If not treated quickly, CRS can become life-threatening.

IMMUNOTHERAPY

A type of therapy that uses your body’s natural defenses (the immune system) to identify, attack, and kill cancer cells.

NEUROTOXICITIES (OR NEUROLOGIC TOXICITIES)

Side effects of the brain and central nervous system.

How Does CAR T Work?

Your immune system is your body's natural defense against disease. It is made up of different types of white blood cells. T cells, or T lymphocytes, are one type of white blood cell. They are your immune system's "fighters." Their job is to seek out and attack viruses, bacteria, and abnormal cells like cancer. They are called "T" cells because they grow in the thymus gland, which sits in the space between your lungs. B cells, or B lymphocytes, are another type of white blood cell. They are called B cells because they grow in your bone marrow.

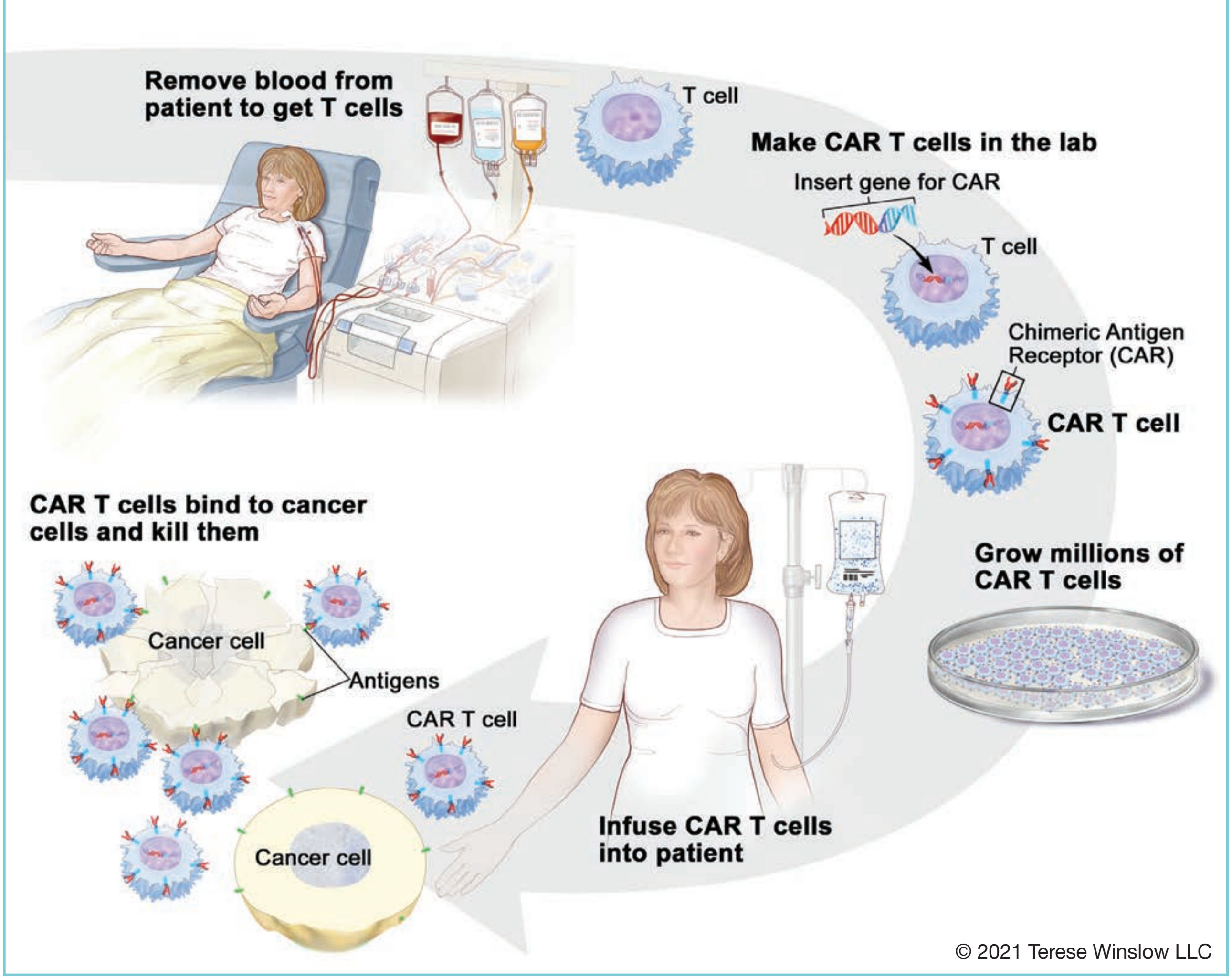
Cancer cells start out as normal cells. But once they become cancerous and start growing out of control, your T cells are not always able to see the cancer cells as a threat and attack them. CAR T helps your T cells find and kill your cancer cells.

CAR T is designed to be a one-time treatment. CAR T cells can remain in the body and continue to be active for a long period of time. After you get the new CAR T cells, you will need a caregiver to be with you 24 hours a day, 7 days a week (24/7), for 4–8 weeks, to support and watch for side effects.

Every patient who is undergoing CAR T receives CAR T cells created in the lab just for them. It works like this:

- T cells are collected from your bloodstream in a fairly simple procedure called apheresis. The T cells may be frozen and kept at the hospital or CAR T center in a special temperature-controlled storage unit until you are ready to receive treatment.
- The T cells are sent to a lab. Chimeric antigen receptors (CARs), which act like a cancer-cell tracking device, are added to your T cells in a complex lab process. With the CAR added, your T cells become CAR T cells. They can more easily find and destroy cancer cells.
- You may get a treatment between apheresis and the infusion of CAR T cells called "bridging therapy." This is to keep the cancer under control while waiting for the CAR T cells to be made in the lab. It will hopefully keep you healthy enough to get your CAR T infusion. Most often, the therapy is chemotherapy or steroids, but radiation is sometimes used.
- The new CAR T cells are grown in the lab for a couple of weeks to make enough CAR T cells for your treatment. Once enough CAR T cells have been grown, they are sent back to your treatment team.
- You will get a brief course of chemotherapy called "conditioning" or "lymphodepleting" chemotherapy before getting the CAR T cell infusion. This is done to destroy regular T cells and give the new CAR T cells more room to operate.
- The CAR T cells are then infused back into you. If there are no delays, the process from apheresis to infusion can take 3–6 weeks.
- Once the CAR T cells are back in your bloodstream, they find and attack your cancer.

CAR T CELL THERAPY



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> "CAR T cells directly harness the power of a patient's own immune system against the cancer. We put a new receptor on the T cells so they will target the cancer cells. We make them 'bionic.' And then we reinfuse those cells back into their body."
>
> — Dr. Jeremy Abramson, Director of the Hagler Center for Lymphoma at Massachusetts General Hospital

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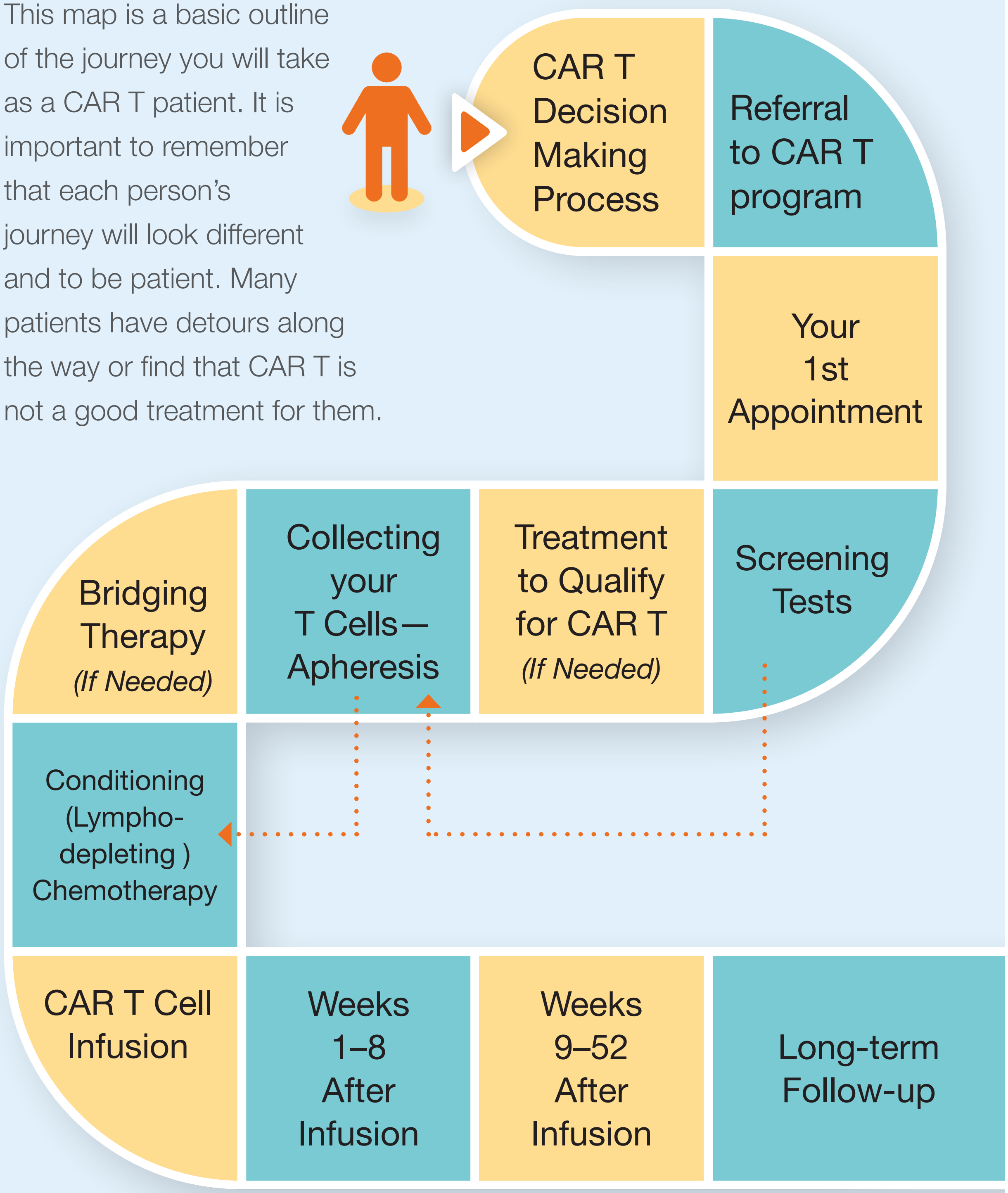
Outline of CAR T Journey

Since CAR T therapy is a process, it is important to follow all steps recommended by your health care team. It is not advised to go to the emergency room or any health care provider's office to request treatment without being referred.

On the next page is a basic outline of a patient's journey, if approved for CAR T therapy. Use the worksheets in Section 3 (pages 142–153) to fill in dates of what you can expect your timeline to look like. You can ask your health care team to help you.

CAR T Patient Journey Map

This map is a basic outline of the journey you will take as a CAR T patient. It is important to remember that each person's journey will look different and to be patient. Many patients have detours along the way or find that CAR T is not a good treatment for them.



CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

Screening Tests

Treatment to Qualify for CAR T *(If Needed)*

Collecting your T Cells—Apheresis

Bridging Therapy *(If Needed)*

Conditioning (Lympho-depleting) Chemotherapy

CAR T Cell Infusion

Weeks 1–8 After Infusion

Weeks 9–52 After Infusion

Long-term Follow-up

The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor's recommendation.

CAR T Journey

CAR T DECISION MAKING PROCESS

Choosing to go through CAR T cell therapy is big decision. There is a lot to consider in deciding if this therapy is right for you. You may be able to explore CAR T therapy at the cancer center where you are currently being treated, or you may be referred to another center that offers CAR T. Choosing to go through CAR T therapy may mean traveling long distances, will require significant caregiver support, and can be costly. Some clinical trials cover all or portions of the costs, such as imaging studies, biopsies, apheresis, CAR T cell production, and hospital stays. Distance, time, and cost are all things to consider in the decision-making process.

REFERRAL TO CAR T

Your primary oncologist refers you to a CAR T program to discuss an FDA-approved CAR T therapy or a clinical trial. If you seek a second opinion at a cancer center, you may learn of CAR T that way.

FIRST APPOINTMENT

Your first appointment allows you to learn more about the cancer center's CAR T program. This appointment will also help the cancer center decide if CAR T is right for you. The treatment team will do some screening tests to make sure you are eligible and healthy enough to go through the treatment.

SCREENING TESTS

During your first appointment with the CAR T team, you will have screening tests to see if this is a good treatment option for you. Additional screening tests may be broken into multiple appointments during your first visit. Timing of your first appointment and screening tests may vary based on the center's availability and the health care provider's schedule.

TREATMENTS TO QUALIFY FOR CAR T (IF NEEDED)

You may need treatment to become healthy enough to participate in CAR T therapy. These kinds of therapies may cause month-long waits before you start the CAR T therapy process. Even if you are healthy enough at this point in the process to start CAR T, you may need bridging treatment to stay healthy long enough to get to the "Infusion" step of CAR T therapy.

COLLECTING YOUR T CELLS FOR APHERESIS

During apheresis you will be hooked up to a machine where your T cells will be separated from your other blood cells. After apheresis, your T cells will be sent to the lab where the "CAR" antigen will be added. The apheresis procedure will take a few hours.

BRIDGING THERAPY (IF NEEDED)

Bridging therapy is cancer treatment given at any step before CAR T infusion to keep you healthy enough to get to infusion. You may need to get bridging therapy multiple times throughout your journey, or you may not need bridging therapy at all. Each round of bridging therapy can last 1 or more months, but in some cases, it may only span 1–2 weeks.

CONDITIONING CHEMO

Before CAR T infusion, you will have conditioning chemotherapy (also known as lymphodepleting chemotherapy) to make room for your new CAR T cells. Conditioning chemotherapy is most often 3 days of chemo and 2 days of rest. However, the timeframe may vary if you are in a clinical trial.

CAR T CELL INFUSION

At infusion, the new CAR T cells will be infused into your bloodstream. The CAR T cells will begin to find and attack the cancer cells in your body. Depending on your CAR T treatment, you may need to go to the hospital to receive the infusion. If it can be done in an outpatient clinic, the infusion appointment may take 20–30 minutes based on your health care team and facility.

WEEKS 1–8 AFTER INFUSION

CAR T infusion can cause side effects. If you are receiving CAR T as an inpatient, you may have to stay in the hospital for up to 1 week following the infusion. If you are receiving CAR T as an outpatient, you can leave the hospital after the infusion. When you leave the hospital, you will need to be monitored closely by your caregiver and stay near the treatment center for at least 4 weeks after infusion. You may need to return to the hospital if you experience serious side effects.

WEEKS 9–52 AFTER INFUSION

You will need to follow-up with the CAR T treatment team, your primary oncologist, or other specialists that understand your specialized needs after the treatment is complete. Your doctor will likely use PET and CT scans to determine whether the therapy worked. If the therapy worked, most often, you will have monthly lab tests or appointments for the first year after infusion. Then, you may have annual appointments for up to fifteen years after infusion.

What Happens if CAR T is Not Right for Me?

Before you can start CAR T therapy, the CAR T center will need to make sure you are healthy enough to go through the therapy. Throughout the process, your CAR T doctor will pay attention to your health. It is possible that your doctor will decide you are not a good fit for CAR T. If that happens, you may wonder what's next. There are other options you can consider.

Sometimes, it may be that you are not a good fit for CAR T right now and you need to go through bridging therapy. Your CAR T doctor will recommend the best bridging therapy for you. The point of bridging therapy is to help you become healthy enough to go through CAR T.

Another option to explore is whether you are a better fit for another CAR T treatment. There are several CAR T drugs available. Or you may want to think about joining a clinical trial for a CAR T drug that is being developed. There are also clinical trials studying other new approaches that may be a better fit for you. In some cases, it may be that you were referred to CAR T too late and you don't have the time to wait for your CAR T cells to be made. You will need to talk to your doctor about other treatment options or maybe look into hospice care.

You may also decide that you do not want to get CAR T treatment. CAR T requires a large investment of time, energy, and usually money for both you and your caregiver. There are also some serious and potentially life-threatening side effects from CAR T. You may decide that CAR T does not match your goals for your treatment plan.

These can be hard decisions to make. To help you decide your next steps, you can use our **Making Treatment Decisions** publication and our **Open to Options** program.

Need Help Deciding Between Treatments? Need Help Deciding if You Want to be Considered for CAR T Therapy? Need Help Deciding Between Aggressive Treatment and Palliative Treatment?

Open to Options® is a free telephone or in-person counseling program provided by trained professionals at the Cancer Support Community. It helps you to:

- Talk about your concerns more clearly to your health care team
- Create a list of questions for your health care team that will help you address your specific needs
- Organize your questions for specialists to help you get the most helpful answers from the right people

Call 844-792-6517 to schedule an appointment or visit **www.CancerSupportCommunity.org/OpenToOptions.**

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CAR T Clinical Trials

CAR T Clinical Trials

Clinical trials are research studies with patients. They are a chance for you to play an active role in healthcare and research, while also helping future patients. The goal of cancer clinical trials is to improve treatments and the quality of life for people with cancer. Your doctor may refer you to a CAR T clinical trial, or you may be interested in finding one on your own. Getting into clinical trials can be complicated and complex. Several cancer nonprofits offer free patient navigators to help you search for clinical trials.

Clinical trials for CAR T can test for different things. Some clinical trials are testing if an already-approved CAR T therapy works in other types of cancers. Others are testing a new type of CAR T therapy. Depending on the type of cancer you have, clinical trials may be the only way for you to receive CAR T therapy. There are also clinical trials that study the management of side effects.

Scientists are trying to discover new and different ways to provide CAR T therapies and other cell therapies. Some of these new approaches include "off-the-shelf" CAR T, TIL, T cell banking, and CAR NK cell therapy.

OFF-THE-SHELF CAR T CELL THERAPY

Instead of using the patient's own T cells, this type of CAR T therapy uses donated healthy T cells from others. These T cells have the CAR protein added to them, which makes them CAR T cells. This type of CAR T therapy is also known as "allogeneic CAR T."

TUMOR-INFILTRATING LYMPHOCYTE (TIL) THERAPY

This is another type of immunotherapy that uses your own T cells. This therapy removes T cells from the tumor that already find and attack cancer cells. These T cells then have special substances added to them to help them grow more quickly and are then added back into your body. These specific T cells are used because they have shown that they can survive and recognize cancer cells. There just may not be enough of them to make them as effective as they can be.

T CELL BANKING

This is a process that allows people to extract their T cells before they need CAR T. This is usually before they have relapsed (cancer has returned) or refractory (cancer doesn't respond to treatment) disease and have been exposed to multiple lines of therapy.

CAR NK CELL THERAPY

Much like T cells, natural killer cells (or NK cells) are part of our immune system and help fight and attack foreign cells and threats. When cancer cells are present, NK cells are not able to work as effectively. This type of therapy adds the CAR protein to the NK cells, to create CAR NK cells. Similar to off-the-shelf CAR T cell therapy, these can potentially be collected from healthy donors.

KEY FACTS ABOUT CLINICAL TRIALS

- People who get their treatment through a clinical trial receive high quality care.
- There are rules about who can join each trial, so they are not available for every patient.
- There are laws to protect the safety of people who join clinical trials.
- No one receives a placebo or "sugar pill" in place of appropriate treatment.
- People who join clinical trials can voluntarily leave at any time and for any reason.
- Some clinical trials may require you to travel away from home, others may be located nearby.
- Not all costs may be covered in a clinical trial, so it's important to ask what costs the trial will cover and what your insurance will cover.
- Some clinical trials offer a health care team that will schedule and keep track of all of your appointments for you. The health care team will closely monitor your health throughout the clinical trial.

CLINICAL TRIAL PHASES

Clinical trials are designed to answer specific research questions. Researchers submit their clinical trial applications to the FDA, who reviews and approves the study protocols. Clinical trails usually move through several phases to test safety, effectiveness, dosage, and other factors.

- **PHASE 1** clinical trials are the 1st test of the dose and safety of a drug. Doctors work with small groups of patients who may have different kinds of cancer. Many phase 1 trials are for people with cancers that have spread to other parts of their bodies.
- **PHASE 2** clinical trials are done if a phase 1 trials showed that the treatment is safe and has signs of activity against 1 or more types of cancer. A phase 2 trial is typically a larger study, often done with specific cancer types. It looks at how well a treatment can work in that type of cancer.
- **PHASE 3** clinical trials are large studies. They involve hundreds or even thousands of patients. For this phase, you will be assigned to get the new treatment or the “standard of care” (current best treatment). To give everyone an equal chance at the new treatment, a computer randomly decides which treatment you will get. The doctor does not have any role in deciding which patients get which treatments and often does not know who is getting the standard of care.
- **PHASE 4** clinical trials are after a drug or new treatment is approved. Doctors continue to monitor it to learn how it works over the long term. They also look to see to see if there are any side effects that appear months or even years after treatment.

Informed Consent

If you agree to join a clinical trial, you will go through a process called informed consent. This is a very formal, step-by-step review of everything involved in the trial. You will be asked to sign a consent form that says you understand the clinical trial and agree to be a part of it. This is a very long (and often complicated) document. This is a good time to ask questions and to bring someone with you as an extra set of eyes and ears. Before starting any clinical trial, your doctor will explain the goals and possible benefits of the study. They will also tell you about any potential risks and side effects that you may have while in the study. Use this time to ask any questions you may have about the clinical trial. Informed consent in CAR T clinical trials may happen before or after apheresis.

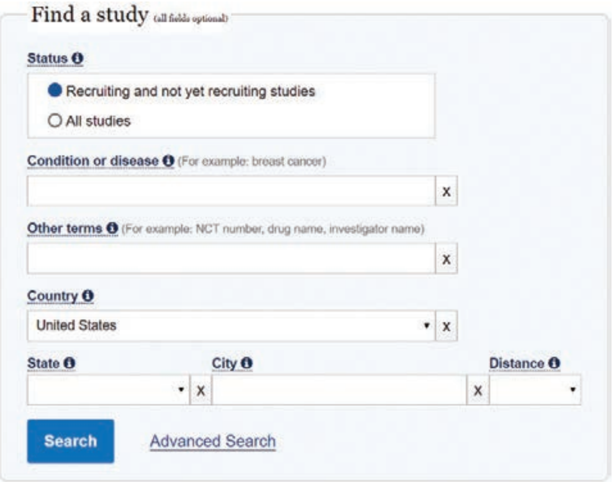
Close Monitoring

If you get CAR T therapy through a clinical trial, you will likely be followed more closely and for a longer period of time by the CAR T team than if you get a "commercial" CAR T therapy (one that is given as it was approved by the FDA).

Finding a CAR T Clinical Trial

Dozens of CAR T clinical trials are now enrolling patients in the U.S. Even if you are not eligible for an approved CAR T treatment, you may be eligible for a clinical trial. You can find a full list of these trials on **www.ClinicalTrials.gov**:

- You will need to put your cancer type and the word "CAR T" in the search form.
- Then, click the boxes that will let you see only the trials taking place in the U.S.
- You can also search for trials in a specific city or state or distance from your home.
- Once you find a clinical trial you are interested in, you can contact the study research staff by phone or email.



Find a study (all fields optional)

Status
● Recruiting and not yet recruiting studies
○ All studies

Condition or disease (For example: breast cancer)

Other terms (For example: NCT number, drug name, investigator name)

Country
United States

State
City
Distance

For more information and help finding a clinical trial, contact CSC's Helpline at 844-792-6517 or visit **www.CancerSupportCommunity.org/Finding-Clinical-Trial**. More resources are also available in Section 3 on page 129.

If You are Considering a Clinical Trial

Read the checklist of questions below in advance of your call/meeting with a clinical trial navigator. During your meeting ask these questions and use the notes section to write down their responses.

QUESTIONS TO ASK THE CLINICAL TRIAL NAVIGATOR	NOTES
☐ What phase is this clinical trial in and what are the goals of this trial?	
☐ Is the CAR T cell therapy being used in this study approved to treat other cancers?	
☐ How is this CAR T cell therapy different from those that have been FDA approved?	
☐ What kinds of tests and screenings are involved in the clinical trial?	
☐ What are the possible side effects I may have when in the clinical trial?	
☐ Will I be hospitalized as part of the clinical trial?	
☐ How did patients do in previous clinical trials of this treatment? How successful was the treatment in previous clinical trials?	
☐ How long will the clinical trial last?	
☐ What does the clinical trial pay for, what will my insurance cover, and what will I need to pay for? *(Note: You might need to have a meeting with the CAR T center Financial Counselor to answer this question.)*	

☐ What will be the difference in my total costs between a CAR T clinical trial and an approved CAR T treatment? *(Note: You might need to have a meeting with the CAR T center Financial Counselor to answer this question.)*	
☐ How will my care be managed after the clinical trial has ended? What tests might I need after the clinical trial?	

Other questions for the Clinical Trial Navigator:

You can learn more about clinical trials on the Cancer Support Community's website: **www.CancerSupportCommunity.org/ClinicalTrials**.

4

CAR T Caregivers & Support Team

All CAR T patients need to have a caregiver, or a trusted team of rotating caregivers, who can be with them 24/7, for at least 4 weeks. This person could be a family member or a friend. For some, this might be more than 1 person. If you don't have 1 caregiver who can stay with you 24/7 for 4 weeks, you may have multiple caregivers who each stay with you for parts of the 4 weeks. If you do not have any caregivers who can stay with you, talk to the social worker at the CAR T center about what other options you have. You may be able to find and hire a healthcare aide to stay with you. After the 4 weeks following the CAR T infusion, you may still need caregiver support, as you will be unable to drive until 8 weeks after your CAR T infusion.

The CAR T treatment team will meet with your caregiver to talk about their role and responsibilities. Most often, centers require that your caregiver is:

- 18 years old or older
- Someone who can commit to be with you 24 hours a day, 7 days a week for 4–8 weeks
- Able to understand what is required of them
- Someone who is responsible and who you can count on
- In good health
- Available for 4–8 weeks
- Has a backup person they can call if something happens to them

The treatment team will want to be sure that your caregiver has certain skills and abilities so they can observe any side effects that you may have and best help you during this process. Your caregiver(s) will also play a significant role in providing you with emotional support throughout the process. As you work to identify a primary caregiver and care support network, use the chart on the next page to outline what support you have in place and any gaps that need to be covered.

Kristin, CAR T survivor, with some of her caregivers on infusion day.

EXPECTATIONS	PRIMARY CAREGIVER	SUPPORT CAREGIVER(S)
☐ Talk to the treatment team about problems or concerns.		
☐ Contact your CAR T team if you have a fever or other side effects that may mean you need to go to the hospital.		
☐ Help get you to and from appointments, either by driving you or by arranging for someone else to drive you.		
☐ Help you take and organize your medication.		
☐ Manage your day-to-day basic living needs.		
☐ Keep your home clean to lower the risk of infection.		
☐ Cook, prepare, or arrange for meal delivery.		
☐ Help you with paying bills.		
☐ Support with child care, elder care, and/or pet care.		

Caregiver Support

To best support you, your caregiver is going to need their own community of support. Your caregiver should seek and identify friends or family members they can turn to. They can also join a caregiver support group or look for support groups online through social media platforms like **MyLifeLine**. See page 127 in Section 3 to view a list of caregiver support programs.

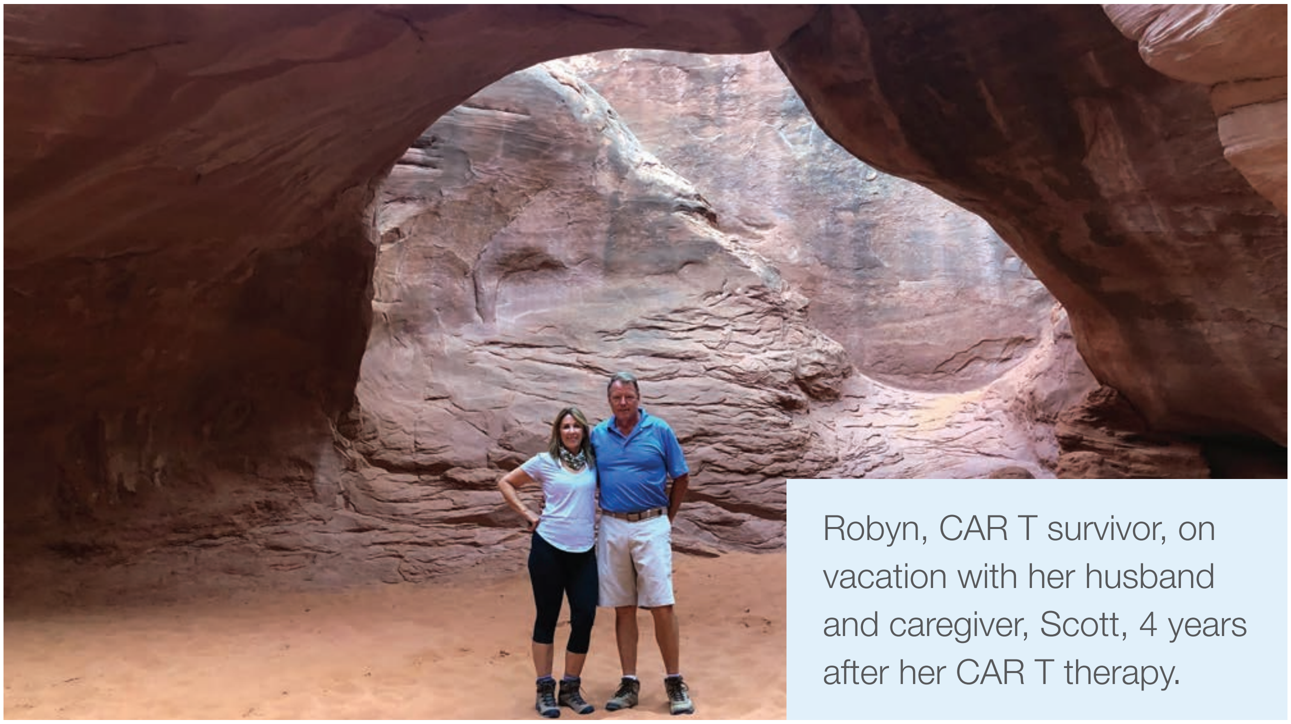
Caregiver Review and Checklist

Being the primary caregiver is an important role and no one expects your caregiver to do it alone. Ask your caregiver to use the checklist below to start preparing for their role. The CAR T team can help provide some of these answers and resources.

I NEED TO KNOW	NOTES
☐ Can I take 4–8 weeks off from work?	
☐ Will I be able to travel with my loved one to their different appointments (1st appointment, apheresis, additional treatments, infusion, follow-up, etc...)?	
☐ Do I need to apply for FMLA or any other type of family medical leave?	
☐ How will I cover my expenses if I am taking off from work?	
☐ Do I have someone who can care for my/our other family members?	
☐ Do I have someone to house or care for the pets while we are away from home or in the hospital?	
☐ Am I emotionally able to support my loved one for 8 weeks during treatment and recovery?	
☐ Who will I reach out to for support?	
☐ What do I need to learn about CAR T cell therapy to be a good caregiver?	
☐ What concerns and questions do I have, and who can I contact to clear them up?	

☐ Where will I stay while my loved one is being treated?	
☐ What will I do for meals during treatment?	
☐ What do I need to bring to the hospital in the case of an emergency?	
☐ Who can take care of my loved one if I am unavailable?	
☐ Can I commit to all 8 weeks of staying with my loved one?	
☐ Can I commit to only part of the 8 weeks? If so, how long and for what part?	

Other questions:



Robyn, CAR T survivor, on vacation with her husband and caregiver, Scott, 4 years after her CAR T therapy.

Gathering Your Support Team

At this point in your journey, you have likely experienced relapses and have side effects from other forms of treatment. You may not be doing well on your current treatment. As you prepare for CAR T, there are many logistics to consider. For example, you and your caregiver may need to make travel arrangements. Your caregiver may be worried about being away from home or family or the need to take time off work. This is a time when you and your caregiver(s) can ask for support from family members and friends.

Think about people in your life (both near your home and near the CAR T center) who can help. It might be family, friends, faith community, support group, or co-workers. Make a list of the specific ways each of them can help (childcare, eldercare, house or pet sitting, meal prep, transportation, laundry, help with planning, etc.). After your CAR T infusion, you likely won't be able to drive for at least 4–8 weeks and will need caregiver support with transportation.

Consider using CSC's **MyLifeLine.org** to help you organize your requests for help to friends, family, and your community while keeping them up to date on your progress. You may also want to use other resources, such as in-person, telephone, or online support groups, helplines, and more to help you out. See page 124 in Section 3 to learn more about these resources.

Kristin, CAR T survivor, and her caregiver, Benny, with other blood cancer survivors. Pictured from left to right: Benny, Kristin, Mary Clare, Sheila, and Roy.

5

Costs and Logistics of CAR T

The CAR T treatment process takes many months. It can affect your finances by making you and your caregiver unable to work for a long period of time. It can affect your family if you have children or parents you take care of. It can also require you to travel to another city or state if CAR T is not offered at a cancer center near you. You may need to secure transportation and lodging frequently throughout this process. Be sure to review the planning steps before each appointment and the resources in Section 3, starting on page 124, to ensure you have secured your logistics. You may also qualify for certain programs that can help with the cost. Working with your social worker can also help. You can learn more about these below or call **CSC's Cancer Support Helpline** at 844-792-6517 for more information and resources.

Cost of Care

CAR T cell therapy is an expensive treatment. On top of the medical costs, it can require a lot of travel and time off from work.

FMLA/TIME OFF WORK

If you or your caregiver are working, you will need to make plans for taking time off work. The Family and Medical Leave Act (FMLA) is a law in the United States that requires employers to give employees job protection and unpaid leave for qualified medical and family reasons. You and your caregiver should talk to your employers to know what options you have. Each job is different, but usually you should reach out to your human resources department and direct manager or supervisor. For planning purposes, the sooner you look into this the better.

You will need to budget for the 4–8 weeks that you will not be working. You will also need to plan for expenses like housing, meals, and transportation.

HOW MUCH WILL THIS COST ME AND MY FAMILY?

Ask to meet with your CAR T center's financial counselor to talk through how much CAR T therapy and any bridging therapy will cost you and what will be covered by your health insurance plan or a clinical trial. Talk to the financial advisor about any and all types of expenses from smaller costs like hospital parking to larger costs like labs and scans.

INSURANCE

The CAR T center will want to know the status of your health insurance before you start treatment. If you have insurance, start the claims process early, as it may take time to evaluate the medical records and approve the payment.

If you don't have a health plan, contact CSC's Helpline at 844-792-6517 or go to **www.CancerSupportCommunity.org/Cost** and see pages 4-5 in our *Frankly Speaking About Cancer: Coping with the Cost of Care* book. If you have Medicare or private health insurance, it is important to learn about the specifics of your policy. Call the phone number on your insurance card and ask them to explain what they would cover. Ask your insurer if travel and lodging support is provided.

TRAVEL COSTS

Health insurance doesn't typically cover CAR T costs for travel, lodging, transportation, and meals, but there are programs you may qualify for. The CAR T center may provide free or low-cost lodging or transportation. Talk to the social worker at your CAR T treatment center. Some nonprofits have programs that reimburse patients for some of their costs. Additionally, drug company assistance programs may help with drug co-pays or reimbursement of some lodging and transportation costs. See page 124 in Section 3 for lodging and transportation resources that you may be able to use.

> “People need to know the financial cost ahead of time and take any financial help that they can get. Save all receipts for food, which can be a big expense. It may seem like a small thing, but sometimes there are programs that will refund your expenses that your social worker may be able to help you find.”
>
> —Dave, Caregiver to CAR T Patient

Asking the right questions is key. This is an important part of your process and something that needs to be considered at every step. You and your care team should work together to ensure there is always a plan in place for where you will stay during every step of your treatment and how you will get to and from treatment sites. Use this chart to ask questions and map out your lodging and transportation plan in the notes column.

QUESTIONS TO ASK YOUR INSURER AND CAR T TEAM ABOUT LODGING AND TRANSPORTATION:	NOTES
☐ Do you offer lodging assistance? ■ If so, is it available to use for all appointments? Or only at certain steps in the process? ■ How can I access it? ■ Is there any assistance available from the drug company or other resources? ■ Is assistance only available as a reimbursement after I have already paid for it?	
☐ Do you offer transportation assistance? ■ If so, is it available to use for all appointments? Or only at certain steps in the process? ■ How can I access it? ■ Does the assistance cover both ground and air transportation? ■ Is there any assistance available from the drug company or other resources? ■ Is assistance only available as a reimbursement after I have already paid for it?	

Other questions:

Section 2

Step-by-Step Guide Through CAR T

CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S
CLUB

How to Use This Section of the Guide

Getting through CAR T requires a lot of planning for you and your caregiver. There are a lot of steps in the process, and each step is different and needs a different level of planning. There are also several steps that are repeated at each phase, such as ensuring you have a translator, if needed, or finding lodging and transportation. Many patients rely on their primary caregivers and other friends to help them plan ahead of time.

This section of the guide can help you plan and prepare for each step of the CAR T process. Each chapter in this section covers a different step in the CAR T patient journey. There are questions you need to ask and actions you need to take before each step, and during each step. To help keep track of these, each step has different color-coded checklists for you to use. In each chapter in Section 2, you will see these checklists:

CHECKLIST COLOR	CHECKLIST TITLE	CHECKLIST PURPOSE
✓ **TAN**	My Path	This checklist is left open for you to fill in the next steps, once you know what they are.
✓ **BLUE**	Questions You Need Answered Before…	This is a list of questions you should ask your cancer care team before this step actually begins.
✓ **PINK**	Get Prepared Before…	This is a list of the actions you need to take before this step actually begins.
✓ **GREEN**	Questions to Ask at…	This is a list of questions you should ask your cancer care team during this step.

The big picture may seem overwhelming. Taking each part of the process step by step can make things easier. Each box has blank spaces for you to write in other questions and issues you may need to address. This is to help you and your primary caregiver—and the friends and family members who are part of your support team – plan ahead.

In between appointments, use your time wisely. Look for the warning symbols that are reminders to skip ahead to the next step so you know what is coming and can get prepared. Each chapter will have a blue checklist "Questions you need answered BEFORE THIS STEP" and the pink "Get prepared BEFORE THIS STEP" checklist, which will explain what to expect and help you plan ahead. If you wait until the appointment to read this chapter, you won't get the full benefit out of this guide.

6

Referral to CAR T Program

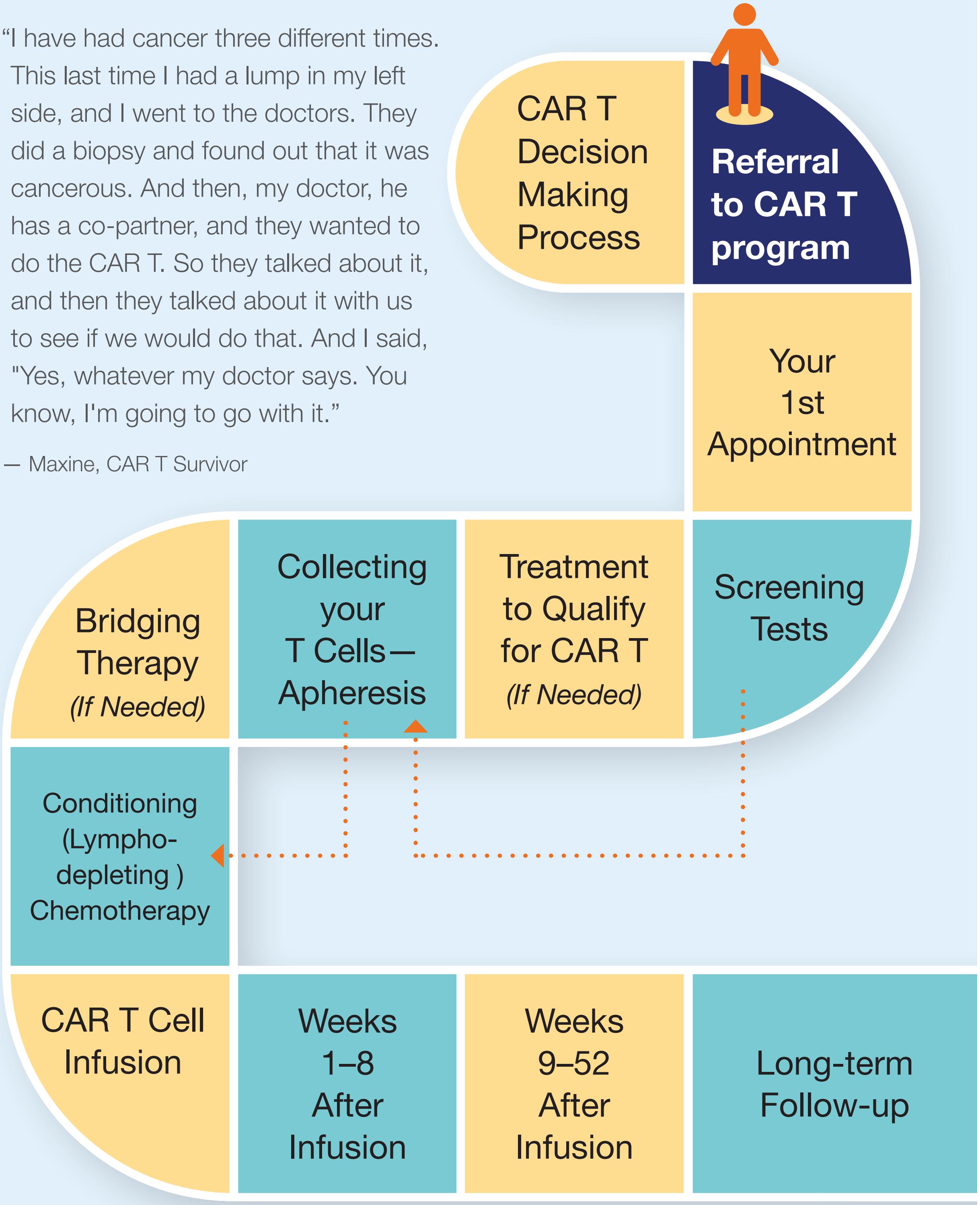
My Path

Either you or your oncologist has started a discussion about considering CAR T cell therapy. This chapter will help you walk through what you need to know.

CAR T Patient Journey Map

> “I have had cancer three different times. This last time I had a lump in my left side, and I went to the doctors. They did a biopsy and found out that it was cancerous. And then, my doctor, he has a co-partner, and they wanted to do the CAR T. So they talked about it, and then they talked about it with us to see if we would do that. And I said, "Yes, whatever my doctor says. You know, I'm going to go with it.”

— Maxine, CAR T Survivor



Referral to CAR T program

CAR T Decision Making Process

Your 1st Appointment

Screening Tests

Treatment to Qualify for CAR T *(If Needed)*

Collecting your T Cells—Apheresis

Bridging Therapy *(If Needed)*

Conditioning (Lympho-depleting) Chemotherapy

CAR T Cell Infusion

Weeks 1–8 After Infusion

Weeks 9–52 After Infusion

Long-term Follow-up

The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor’s recommendation.

Referral to a CAR T Program

To see if you can have CAR T, you must be seen by a CAR T program. Most often, it is your primary oncologist who will refer you to a CAR T program or an oncologist that you have met with to get a second opinion. Nearly, all patients being considered for CAR T will have already had multiple other unsuccessful cancer treatments. This can include chemotherapy, radiation, and stem cell (or bone marrow) transplant.

Your primary oncologist may refer you to a CAR T treatment team in the same cancer center where you are being treated. Or it may be to a cancer center in another city or state. Remember that CAR T doesn't work for all patients. The CAR T team will need to see you in person (or sometimes via telehealth) to conduct a full medical assessment and review your medical history to see if you are a good fit for the treatment. They can't decide if CAR T is right for you by only looking at your medical records. Sometimes your primary oncologist may help complete the medical assessment. The CAR T team may also want to meet with your caregiver to make sure they understand their role as you are treated with CAR T.

In some cases, you may need treatment to become healthy enough to participate in CAR T therapy. These therapies may cause a delay of one or several months before you can start the CAR T therapy process. Or you may be healthy enough at this point in the process to start CAR T but need bridging treatment to stay healthy long enough to get to the infusion step of CAR T therapy. We will talk more about bridging therapy in future chapters.

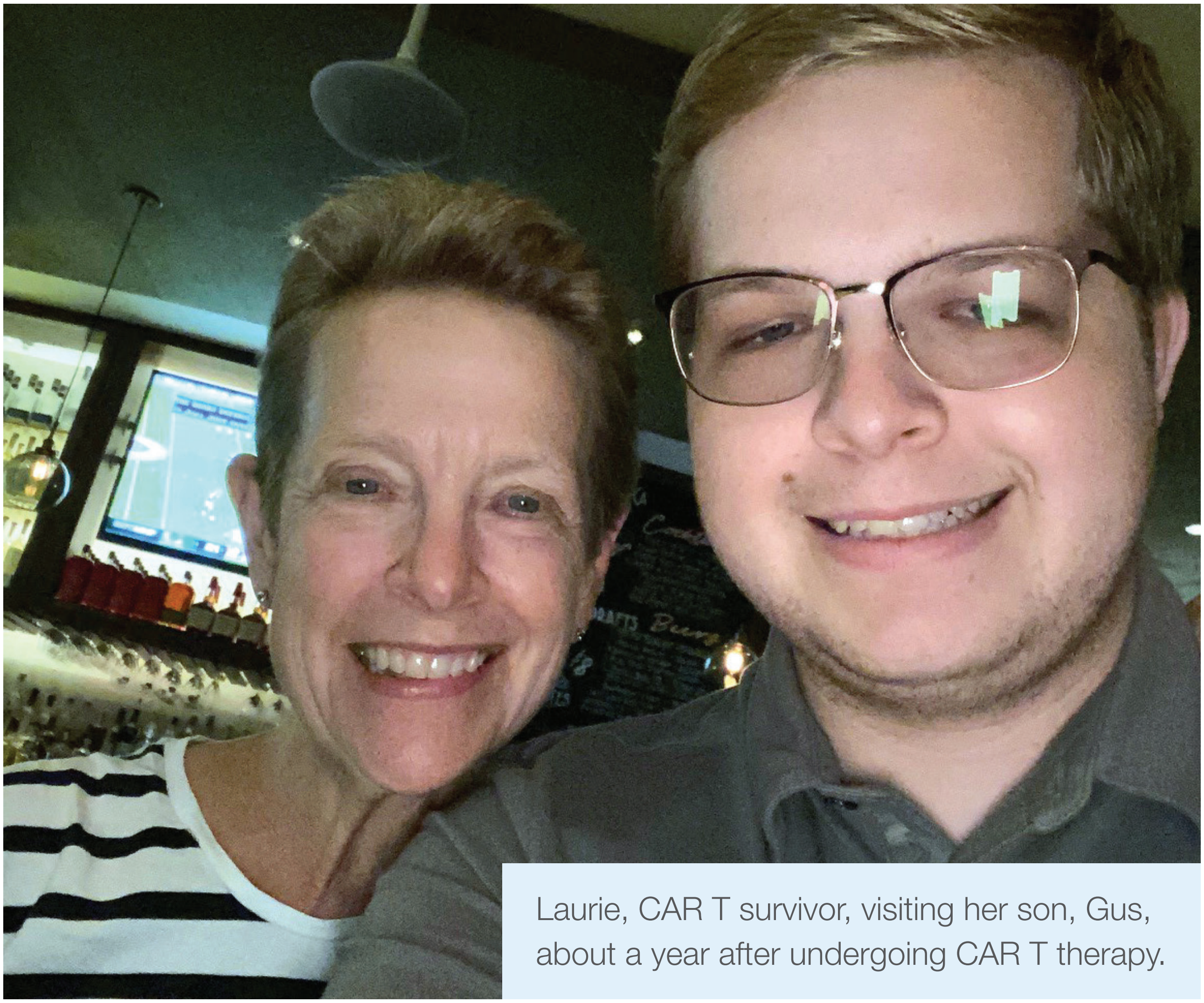
After the first visit with the CAR T team, most people go back home. They return later to start treatment once they are approved to move forward.

You may still be dealing with side effects of prior therapies. Be sure to tell all your health care providers about them, so they can help manage them. You may even want to ask your providers for a referral to a palliative care specialist, someone who only helps treat side effects to make you feel better. For more information on coping with cancer treatment side effects, go to **www.CancerSupportCommunity.org/Managing-Side-Effects**.

> "Emotionally the social worker was quite helpful. After that, I went to some wraparound services from the hospital, just to help with the emotional roller coaster after cancer. Even though after you're considered in remission, you still have those fears and anxieties and just learning to cope with your new norm. And that's always a challenge."
>
> — Lisa, CAR T Patient

HOW ARE YOU FEELING EMOTIONALLY?

People being referred to CAR T therapy and their caregivers report a wide range of emotions at this step in the process. You may be feeling anxiety, sadness, anger, and frustration that previous treatments didn’t work. You may feel grief or abandonment at the idea of leaving your current cancer care team to pursue CAR T therapy. You may feel hopeful that this different approach may be just what you need. You may feel overwhelmed by the prospect of starting a new therapy with a brand-new care team. Likely, you will be feeling many of these emotions and others, all at the same time. Whether you are the patient or the caregiver, reach out and get the support you need. Reach out to CSC’s CAR T **Cancer Support Helpline®** at 844-792-6517, other helplines, online support groups, other resources mentioned in Section 3, and/or trusted members of your larger support network who are willing to listen.



Laurie, CAR T survivor, visiting her son, Gus, about a year after undergoing CAR T therapy.

QUESTIONS TO ASK AT

Referral to a CAR T Program

QUESTIONS TO ASK	NOTES
☐ Who is my contact person for the CAR T center and what is their contact information?	
☐ Will you make my appointment at the CAR T center or do I need to make it?	
☐ Am I healthy enough to travel if the center is not near my home?	
☐ Is my referral for an approved treatment or for a clinical trial?	
☐ Will my insurer cover any of the travel and lodging (if away from home) expenses to get to the first appointment? *(Note: Your insurer's Finance Department will be able to answer this question for you if the CAR T doctor does not know. You can call the customer service number that is on the back of your medical insurance card.)*	
☐ Is there another treatment that I should consider over CAR T?	
☐ Is there a CAR T drug in clinical trials that might be better for me compared to the approved CAR T treatments on the market?	
☐ If the CAR T team does not accept me, what is my next step in the treatment process?	

Other questions:

NEXT STEP PLANNING

Your next step is **your 1st appointment**. You can read more about this in Chapter 7. There are 3 things you MUST do before getting to this 1st appointment.

☐ Turn to the next chapter and complete what you can in the tan checklist, “My Path.”

☐ Go to page 38 and complete the blue checklist, “Questions You Need Answered Before Your 1st Appointment.”

☐ Lastly, complete the pink checklist on page 40, “Get Prepared Before Your 1st Appointment.”

7

Your 1st Appointment

My Path

☐ My referring doctor’s office is setting up a CAR T screening appointment for me.
I should hear back from my doctor's office by *(date)* ____________________ .

☐ If I don’t hear back by then, I should call *(name)* ________________________
at *(number)* ______________________________.

☐ I need to call to get a CAR T screening appointment. Contact information for
CAR T center *(number)* ____ .

☐ My CAR T screening appointment is set for *(date & time)* _________________
______________________ at *(name of CAR T center)* __________________ .

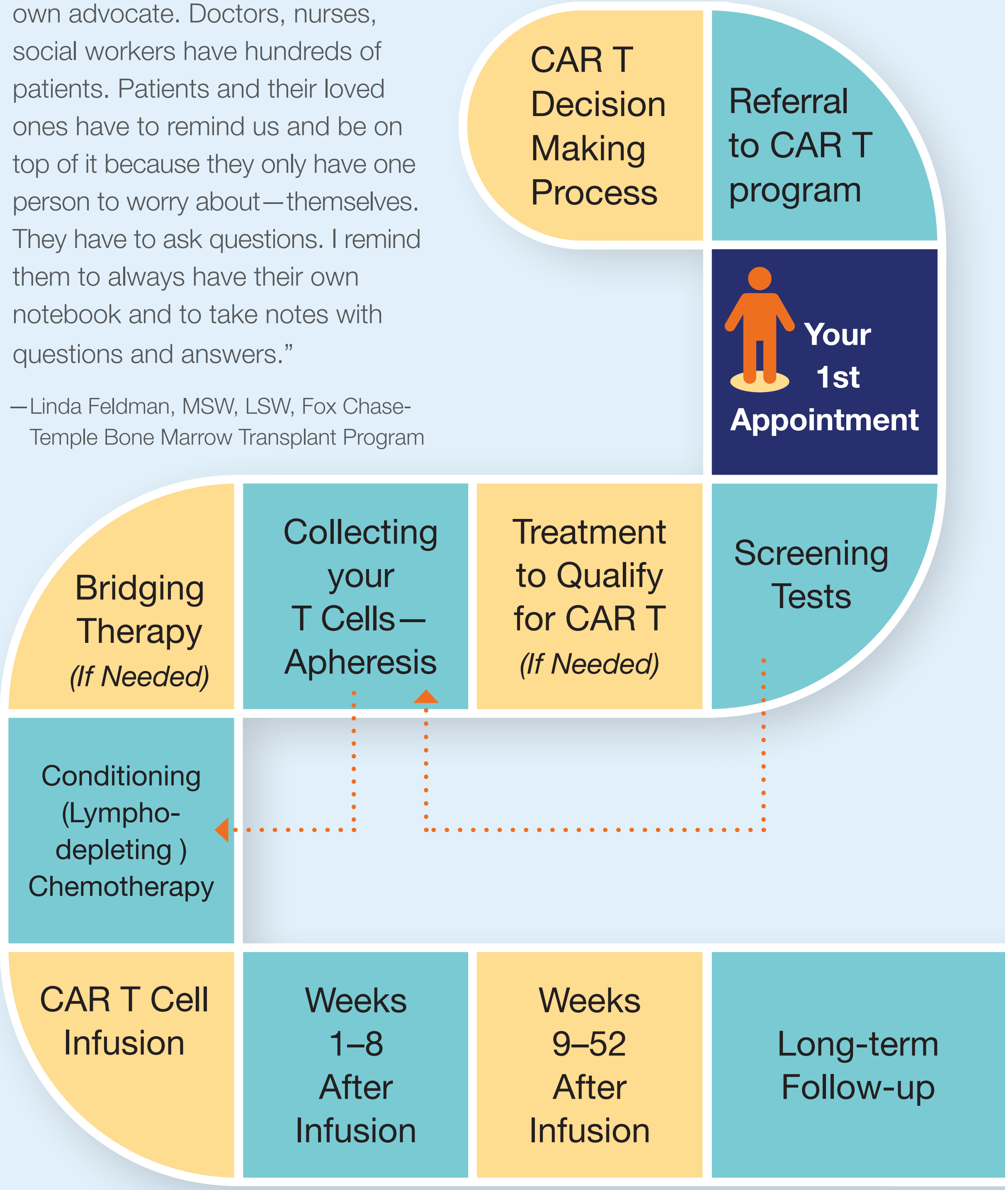
☐ The address for my appointment is __________________________________
____ .

☐ The name of the CAR T doctor I am meeting is _________________________
____ .

☐ Other ____

CAR T Patient Journey Map

> "Patients and families need to be their own advocate. Doctors, nurses, social workers have hundreds of patients. Patients and their loved ones have to remind us and be on top of it because they only have one person to worry about—themselves. They have to ask questions. I remind them to always have their own notebook and to take notes with questions and answers."
>
> —Linda Feldman, MSW, LSW, Fox Chase-Temple Bone Marrow Transplant Program



CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

Screening Tests

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Bridging Therapy *(If Needed)*

Conditioning (Lympho-depleting) Chemotherapy

CAR T Cell Infusion

Weeks 1–8 After Infusion

Weeks 9–52 After Infusion

Long-term Follow-up

The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor's recommendation.

Your 1st CAR T Appointment

Your 1st appointment allows you to learn about the cancer center's CAR T program. It also helps the CAR T team decide if this treatment option is right for you. Not all patients are able to get CAR T. The treatment team will need to do screening tests to make sure that you are a good fit.

Depending on your cancer center, additional screening tests may be broken up into multiple appointments during your first visit to the center. Or, you may have to return at a later date for the additional screening tests. Your doctor may also say you need treatment to become healthy enough to participate in CAR T therapy. These kinds of therapies may cause month-long waits before they recommend you start the CAR T therapy process. Or you may be healthy enough at this point in the process to start CAR T but need bridging treatment to stay healthy long enough to get to the Infusion step of CAR T therapy.

At this appointment or after your screening test results are back, you may learn:

- You are not a good candidate for CAR T treatment.
- You need to have more tests done to see if you are healthy enough to have CAR T.
- You can be treated at this cancer center with an approved CAR T therapy.
- You can be treated at this cancer center in a clinical trial.
- You should go to a different CAR T program or different cancer therapy program, and who to contact.

It can be stressful to not know if you will be accepted to the CAR T program or if your insurance will pay for this treatment. You may be overwhelmed with the logistics that this treatment requires. Talk to members of your treatment team to get answers to questions you have. You can also try getting advice from others who have had CAR T and by joining an online support group (see page 126 for support resources).

WHAT TO BRING TO YOUR APPOINTMENTS?

☐ Insurance cards

☐ List of prescribed medications, dosage, how often you take them, and what they are treating

☐ List of over-the-counter medications and vitamins, dosage, how often you take them, and what they are being used for

☐ Medical records and tests (You can request to have records sent to you or a contact at the new location. Medical records can be requested in digital and/or hardcopy.)

☐ Photo ID

☐ Your caregiver(s)

☐ This guidebook

QUESTIONS YOU NEED ANSWERED BEFORE
Your 1st Appointment

Answer these questions below before your 1st appointment. If you are working with a social worker or navigator, they may be able to help you get the answers you need. If you do not have either, ask your CAR T center if they have one you can work with.

QUESTIONS TO ASK	NOTES
☐ How long will my appointment be?	
☐ What do I need to bring to my appointment?	
☐ What does my caregiver need to know for this appointment?	
☐ If we need to spend the night, where do you suggest we stay?	
☐ Do you have financial assistance for travel and lodging? ■ If so, can I get the assistance in advance? Or can I get reimbursed? Who do I contact for this assistance?	
☐ If we stay in a hotel, how can we get to the hospital? Is there a hospital shuttle?	
☐ If I drive, where can I park? Can I get reimbursed for parking?	
☐ Is there a financial counselor who can help me find out if my insurer has pre-approved this appointment?	

☐ Is this referral for an FDA-approved CAR T treatment or for a CAR T clinical trial? If it is a clinical trial, which phase is this clinical trial?

☐ How do I get a translator, if needed?

☐ Will I have any screening tests during this visit? *If the answer is yes, here are additional questions about the tests:*

- How long will each test take? What do I need to bring to each test or how do I need to prepare for each test?
- Can you fit as many of my tests as possible into one visit?
- Do any of the tests need to be pre-approved by my health plan?
- Do I need to do anything to prepare for the screening tests?
- Are there any foods, drinks, or medications that I should avoid before the screening tests?

Other questions:

GET PREPARED BEFORE

Your 1st Appointment

Use this list to help you and your caregiver organize the tasks you need to complete before your 1st appointment. Many of these items are similar to the questions listed in the previous checklist. Now that you have the answers to the questions in the previous checklist, you can use this checklist as a "to-do list" before your 1st appointment.

WHAT WE NEED TO PLAN, DECIDE, AND DO	NOTES
☐ Make plans and reservations to get me and my caregiver to and from the CAR T center, including airfare, train fare, taxi or rideshare, gas, and/or parking.	
☐ If we need to stay overnight, determine where will we stay, how much will it cost, and how can we make a reservation.	
☐ Budget how much we will need to spend for meals and other expenses while we are traveling.	
☐ Look into transportation, lodging, and financial assistance, if needed. Look at the resources in Section 3, which start on page 124.	
☐ Decide what we need friends and family to help with at home so we can get to my CAR T appointment. ■ Childcare ■ Eldercare ■ House or pet-sitting ■ Help with planning ■ Mail collection	

☐ Determine if my loved one or I need to request time off work. Decide if we should talk to our employer(s) about FMLA.	
☐ Contact my insurer to see if I need a pre-approval for the first appointment.	
☐ Double check that the CAR T program has my medical records.	
☐ Learn what we can about CAR T (see **www.CancerSupportCommunity.org/CART**).	
☐ Write down any questions my loved one or I may have about CAR T.	
☐ Make a list of the medications (prescribed and over the counter), vitamins, herbs, and supplements I am taking, how much I take, how often I take them, and what it is treating. Bring this list to the appointment.	

Other planning needs:

The CAR T Treatment Team

The treatment team includes doctors, nurses, and other specialists who can guide you through CAR T. Use page 122 in Section 3 to write in contact information each time you meet a new person on your treatment team. Your CAR T team can include:

- A CAR T cell therapy physician (oncologist or expert in stem cell transplants)
- Cellular therapy coordinators and nurse navigators (nurses, advanced practice nurses (APNs), and physician assistants (PAs) who coordinate your CAR T care)
- Clinical trial navigator
- Physicians, nurses, and residents who will provide care while you are in the hospital
- Neurologists and infectious disease specialists who will monitor and treat your side effects
- An intensive care team, if you are admitted to the intensive care unit (ICU)
- Social workers who can help you coordinate your care, find resources and financial support, and manage logistics and cost of care
- Financial counselor
- Appointment scheduler

TALK TO A SOCIAL WORKER

Many cancer centers have social workers on staff to help patients and caregivers. A social worker may be able to help you and your caregiver:

- Find resources and support
- Find a place to stay while you are getting CAR T
- Find transportation during treatment
- Explain your treatment to friends or family members
- Help your caregiver know what to expect during your treatment
- Get disability benefits
- Get family leave benefits
- Find financial assistance
- Help you work with the hospital's finance department
- Work with your CAR T team to ensure clear communication
- Help you cope with stress and emotional concerns

QUESTIONS TO ASK AT

Your 1st Appointment

QUESTIONS TO ASK	NOTES
☐ What is the CAR T process like at this center? Does it match the basic process outlined in chapter 2, starting on page 7?	
☐ What experience does your team have with CAR T? How many past CAR T patients achieved remission?	
☐ Can you walk me through the expected timeline if I am eligible? *(Ask them to walk you through the basic process outlined on page 9.)*	
☐ Do I need to have any screening tests done before you can decide if CAR T is right for me? ■ What tests would I need? When? And where will the tests happen?	*Write this information on page 49.*
☐ How long will each test take? ■ What do I need to bring to each test? ■ How do I need to prepare for each test?	
☐ How many of my tests can you fit into one visit? Is it possible to fit all of my tests into one visit?	
☐ Do any of the screening tests need to be pre-approved by my health insurance company?	
☐ Who should my main contact person be if I have questions or problems between appointments? ■ How do I get in touch with them outside of office hours?	*Write this information in the inside front cover.*

☐ Do I live close enough to the CAR T center that I can go home when I am not in the hospital?

☐ Do you have a social worker and financial counselor who can help me and my caregiver with planning and costs? If yes, what is their contact information?

☐ Are there any better treatment options for me to consider, such as a stem cell transplant or other clinical trials?

☐ If I choose a different treatment option now, will I be able to receive CAR T in the future, if needed?

☐ Are my heart, lungs, and other organs healthy enough for me to have CAR T?

- If not, is there therapy I need first to get healthy enough?
- What is the timeline for that therapy?

☐ If I need bridging therapy, where will I be treated and what therapy will I get?

☐ If I am not able to have CAR T here, are you able to refer me to another CAR T program?

☐ What if CAR T does not work for me? What would be the next steps?

Other questions:

NEXT STEP PLANNING

Your next step will be to have **screening tests** for CAR T. You can read more about this in Chapter 8. There are 3 things you MUST do before having screenings for CAR T.

☐ Turn to the next chapter and complete what you can in the tan checklist, "My Path."

☐ Next, go to page 50 and complete the blue checklist "Questions You Need Answered Before the Screening Tests."

☐ Lastly, complete the pink checklist on page 52 "Get Prepared Before the Screening Tests."

8

Screening Tests

My Path

☐ After my first appointment, I learned I am not a good fit for CAR T. I will speak to my primary oncologist about different treatment options or to another center I have been referred to for clinical trials.

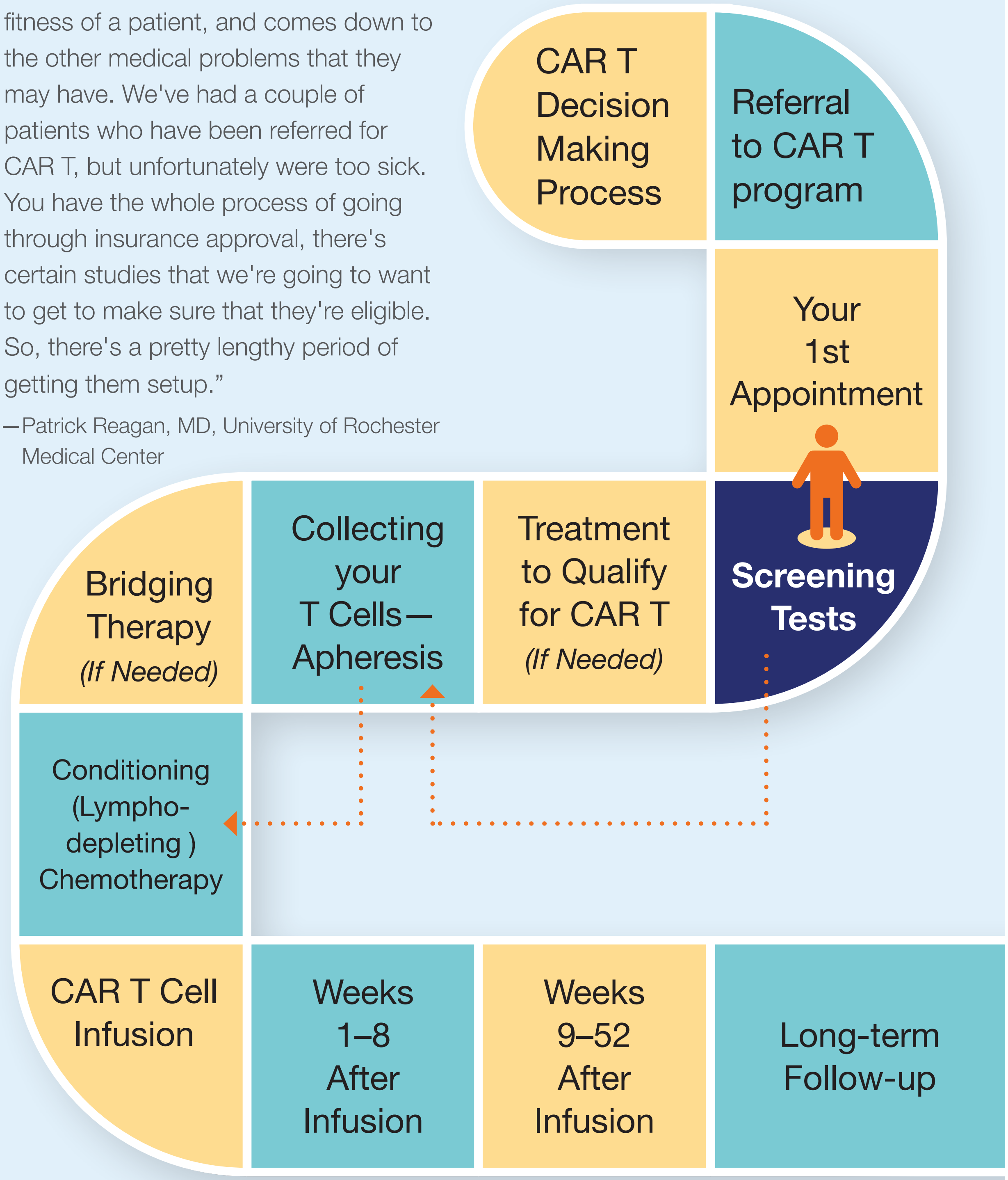
☐ I will need to complete screenings tests. (Use the chart of page 49 to keep track of your screening tests.)

☐ The CAR T team is setting up the screening tests for me. If I don't hear back by *(date)* ____________________, I should call *(name)* ______________________________ at *(number)* ____ .

☐ Other ____

CAR T Patient Journey Map

> "I think a lot of times it comes down to fitness of a patient, and comes down to the other medical problems that they may have. We've had a couple of patients who have been referred for CAR T, but unfortunately were too sick. You have the whole process of going through insurance approval, there's certain studies that we're going to want to get to make sure that they're eligible. So, there's a pretty lengthy period of getting them setup."
>
> —Patrick Reagan, MD, University of Rochester Medical Center



The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor's recommendation.

Screening Tests

You will need to have screening tests to see if CAR T is a good option for you. Use this table to keep track of the screening tests you need, the date/time/location for the screening tests, and any preparation that is required.

TEST	YES	NO	DATE & TIME OF TEST	TEST LOCATION	PREPARATION REQUIRED
CT Scan	☐	☐			
PET Scan	☐	☐			
Biopsy	☐	☐			
Echocardiogram	☐	☐			
Bloodwork	☐	☐			
Other ______________	☐	☐			
Other ______________	☐	☐			
Other ______________	☐	☐			

You may find that you need more biopsies, scans, and tests than the ones listed above to know if you can have CAR T cell therapy. It can be frustrating and feel like things are moving slowly. But the CAR T team needs to make sure that CAR T is the right treatment option for you.

QUESTIONS YOU NEED ANSWERED BEFORE THE

Screening Tests

QUESTIONS TO ASK	NOTES
☐ How do I make the appointments for all the CAR T screening tests?	
☐ Can these screening tests be completed with my home doctor to minimize the length of my stay near the CAR T center?	
☐ What screening tests are needed and how long will each screening test take?	
☐ Do any of the screening tests need to be pre-approved by my health plan?	
☐ How can I best prepare for each test? ■ Are there any testing requirements like a food or liquid fast? ■ Are there any medications I should take or avoid? ■ Is there anything that I would need to bring to each test?	
☐ Is there a financial counselor who can help me plan and manage the costs of my CAR T treatment? If yes, what is their contact information?	
☐ Does my caregiver need to come with me for the screening tests? ■ Can someone else come with me and help me get to these tests?	
☐ If we need to spend the night, where do you suggest we stay?	

☐ Is financial assistance available for travel and lodging? ■ If yes, can I get the assistance in advance? Or do I need to get reimbursed afterwards?	
☐ If we stay in a hotel, how can we get to the hospital for testing? Are there shuttles or do you offer travel vouchers?	
☐ How do I get a translator, if needed?	

Other questions:

GET PREPARED BEFORE THE
Screening Tests

WHAT WE NEED TO PLAN, DECIDE, AND DO	NOTES
☐ Figure out how many times I will need to come back to the CAR T center for additional screening tests between now and apheresis.	
☐ Identify who will come with me and help me get to these additional screening tests.	
☐ Determine where I will stay, travel arrangements to the CAR T center, transportation to and from the hospital, and any parking costs.	
☐ Look into transportation, lodging, and financial assistance, if needed.	
☐ Decide what we need friends and family to help with at home so I can get to my CAR T screening tests. ■ Childcare ■ Eldercare ■ House sitting ■ Pet-sitting ■ Help with planning ■ House care (Ex: garbage collection, watering plants, mail collection)	
☐ Contact my health plan to see if I need pre-approval for any of these screening tests.	
☐ Request time off from work. Remind my caregiver to also do so, if needed.	

☐ Talk to my employer about FMLA. Remind my caregiver to also do so, if needed.	
☐ Learn what we can about CAR T treatment (see **www.CancerSupportCommunity.org/CART**) and write down any questions for the CAR T team.	

Other planning needs:

QUESTIONS TO ASK AT THE Screening Tests

QUESTIONS TO ASK	NOTES
☐ When will my screening test results be available? How will I be notified when the results are in?	
☐ How can I get a copy of my screening test results?	
☐ Who can I call to learn more about the screening test result status? What is their contact information?	
☐ Who will explain my screening test results to me and what they mean for my CAR T treatment?	

Other questions:

NEXT STEP PLANNING
(IF YOU NEED TREATMENTS TO QUALIFY FOR CAR T)

If needed, your next step may be **treatments to qualify for CAR T**. You can read more about these treatments in Chapter 9. There are 3 things you MUST do before having treatments for CAR T.

☐ Turn to the next chapter and complete what you can in the tan checklist, "My Path."

☐ Next, go to page 60 and complete the blue checklist "Questions You Need Answered Before Treatment to Qualify for CAR T."

☐ Lastly, complete the pink checklist on page 61, "Get Prepared Before Treatment to Qualify for CAR T."

NEXT STEP PLANNING
(IF YOU DO NOT NEED TREATMENTS TO QUALIFY FOR CAR T)

If you do not need treatments to qualify for CAR T, then your next step will be collecting your T cells, also known as **apheresis**. You can read more about apheresis in Chapter 10. There are 3 things you MUST do before having apehersis.

☐ Turn to the next chapter and complete what you can in the tan checklist, "My Path."

☐ Next, go to page 66 and complete the blue checklist, "Questions You Need Answered Before Apheresis."

☐ Lastly, complete the pink checklist on page 68, "Get Prepared Before Apheresis."

9

Treatment to Qualify for CAR T *(If Needed)*

This chapter is for patients who may need additional treatments to qualify for CAR T. If you do not need additional treatments, skip to chapter 10.

My Path

☐ I do not need any treatments to qualify for CAR T. I should move to Chapter 10, *Collecting Your T Cells – Apheresis*

☐ I will need to complete additional treatments to qualify for CAR T.

If you need additional treatments, you can download this book and print a blank version of this chapter to help you plan for your next therapy at www.CancerSupportCommunity.org/CART.

☐ The CAR T team is setting up the treatments for me. If I don't hear back by

(date) ____________________, I should call *(name)* ________________________________

at *(number)* ____ .

☐ I need to setup my own appointment for treatment with my referring oncologist.

I should call my oncologist by *(date)* ________________________________

at *(number)* ____ .

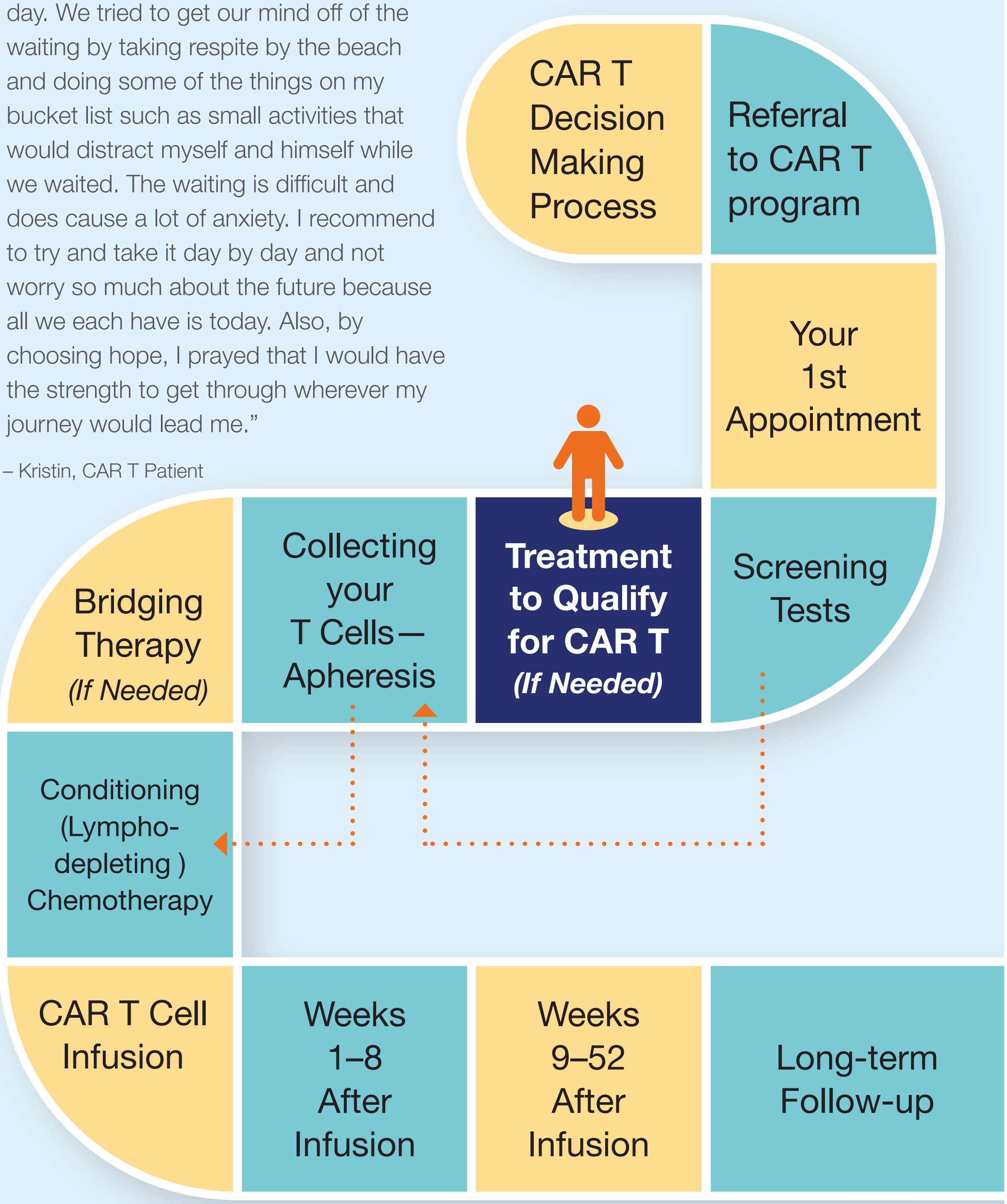
☐ My appointment is scheduled for *(date and time)* ______________________

at *(address)* ____ .

☐ Other ____

CAR T Patient Journey Map

> “My caregiver and I really took it day by day. We tried to get our mind off of the waiting by taking respite by the beach and doing some of the things on my bucket list such as small activities that would distract myself and himself while we waited. The waiting is difficult and does cause a lot of anxiety. I recommend to try and take it day by day and not worry so much about the future because all we each have is today. Also, by choosing hope, I prayed that I would have the strength to get through wherever my journey would lead me.”
>
> – Kristin, CAR T Patient



CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

Screening Tests

Treatment to Qualify for CAR T *(If Needed)*

Collecting your T Cells—Apheresis

Bridging Therapy *(If Needed)*

Conditioning (Lympho-depleting) Chemotherapy

CAR T Cell Infusion

Weeks 1–8 After Infusion

Weeks 9–52 After Infusion

Long-term Follow-up

The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor’s recommendation.

You may need treatment to become healthy enough to participate in CAR T therapy. These kinds of therapies may cause month-long waits before you can start the CAR T therapy process. Or you may be healthy enough at this point in the process to start CAR T but need bridging treatment to stay healthy long enough to get to the Infusion step of CAR T therapy.

You may be able to receive this treatment near your home from your referring oncologist. Or, more likely, you will receive it at the CAR T center's location. If you do not live nearby, you will have to travel to and may need to stay near the CAR T center. You and your caregiver will need to plan these travel and lodging logistics.

Laura, CAR T survivor, with her husband, Robert, who was her caregiver throughout CAR T.

QUESTIONS YOU NEED ANSWERED BEFORE

Treatment to Qualify for CAR T

QUESTIONS TO ASK	**NOTES**
☐ Why am I not able to get CAR T therapy now?	
☐ What treatment(s) do I need to qualify for CAR T? And for how long?	
☐ What goals do I have to meet, so that I am eligible for CAR T?	
☐ What are the potential side effects of these treatments?	
☐ Do I have to complete my treatments to qualify for CAR T in a certain time frame?	
☐ When will I be contacted if I become eligible for CAR T?	
☐ If I have questions throughout the treatment process, who should I contact and what is their contact information?	
☐ Is there a financial counselor who can help me manage the costs of my treatment? If yes, what is their contact information?	
☐ How do I get a translator, if needed?	

Other questions:

GET PREPARED BEFORE

Treatment to Qualify for CAR T

WHAT WE NEED TO PLAN, DECIDE, AND DO	NOTES
☐ Determine if my treatments be done with my referring oncologist or another local team.	
☐ Figure out who will come with me and help me get to my qualifying treatment appointments.	
☐ Arrange transportation to and from treatment.	
☐ Look into transportation, lodging, and financial assistance for treatment, if needed.	
☐ Decide what we need friends and family to help with at home so I can get to my qualifying treatment appointments and to recover. ■ Childcare ■ Eldercare ■ House sitting ■ Pet-sitting ■ Help with planning ■ House care (Ex: garbage collection, watering plants, mail collection)	
☐ Contact my health plan to see if I need a pre-approval for any of these treatments.	
☐ Request time off from work. Remind my caregiver to also do so, if needed.	

Other planning needs:

If you learn that you must wait 1 or more months to continue with CAR T treatment, you may experience distress or disappointment. As you continue to get treatments to qualify for CAR T, you may experience fatigue, nausea, vomiting, dehydration, low blood count and other physical side effects from the treatment.

QUESTIONS TO ASK AT

Treatment to Qualify for CAR T

QUESTIONS TO ASK	NOTES
☐ What will be the schedule for these treatments?	
☐ Will you be in contact with the team giving me these treatments or do I need to stay in contact with the CAR T center? If I need to stay in contact with the CAR T center myself, who should I contact?	
☐ If I have questions during my treatment, who do I contact? What is their contact information?	
☐ Is my next step apheresis?	
☐ Who is my contact person for apheresis? What is their contact information?	

Other questions:

NEXT STEP PLANNING

Your next step will be collecting your T cells also known as **apheresis**. You can read more about apheresis in Chapter 10. There are 3 things you MUST do before having apheresis.

- ☐ Turn to the next chapter and complete what you can in the tan checklist, “My Path.”
- ☐ Next, go to page 66 and complete the blue checklist “Questions You Need Answered Before Apheresis.”
- ☐ Lastly, complete the pink checklist on page 68, “Get Prepared Before Apheresis.”

10

Collecting Your T Cells—Apheresis

My Path

☐ My treatment team will set up an apheresis appointment for me. If I don't hear back by *(date)* ________________, I should call *(name)* __________________________ at *(number)* ____ .

☐ If I don't feel well prior to my appointment, I should call *(name)* _______________ ___________________________ at *(number)* ____________________________________ .

☐ My apheresis appointment is set for *(date & time)* _____________________________ _______________________ at *(name of center/building)* _________________________ .

☐ The address for my appointment is ____ .

☐ Other ____
____

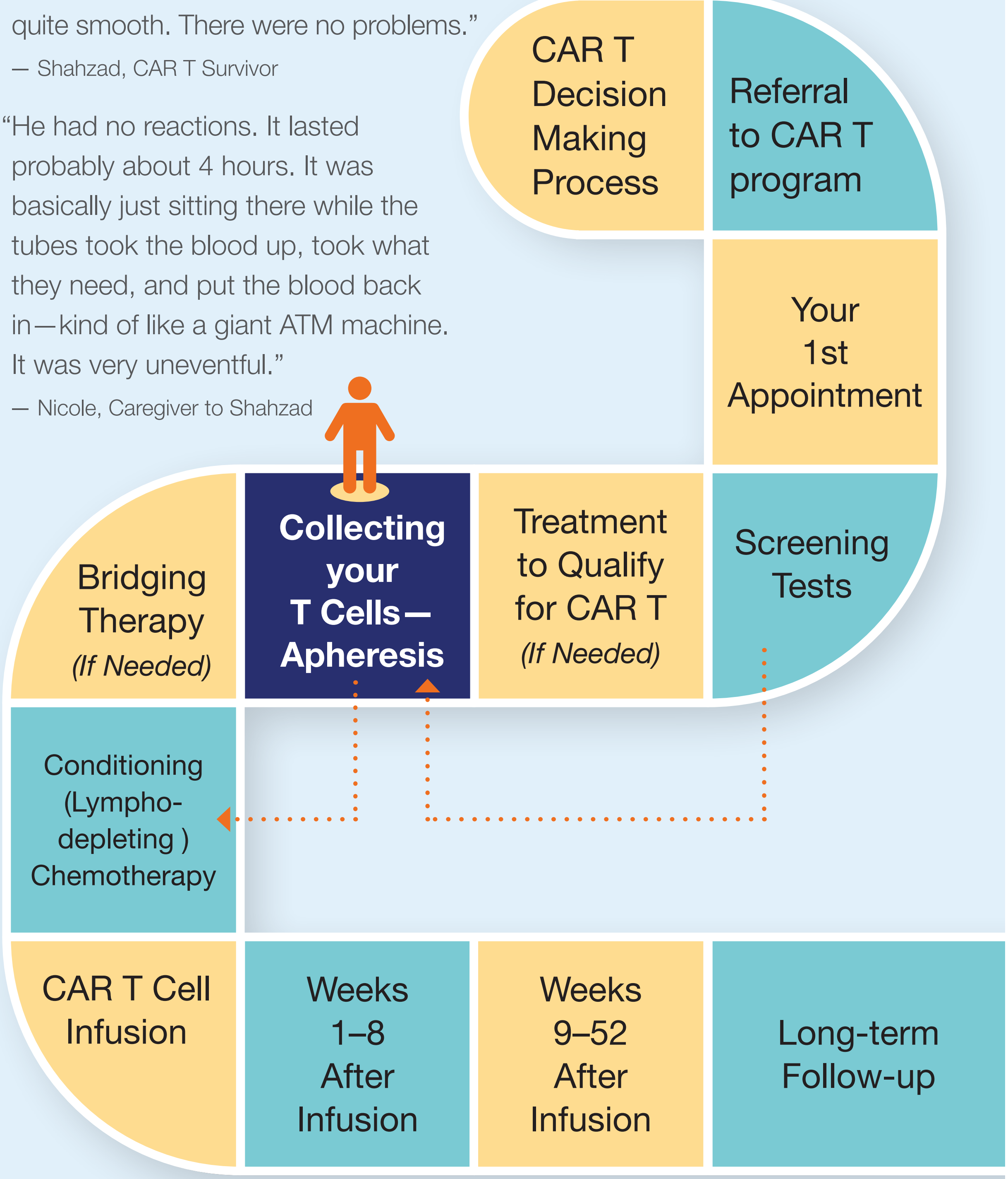
CAR T Patient Journey Map

"The apheresis process was actually quite smooth. There were no problems."

— Shahzad, CAR T Survivor

"He had no reactions. It lasted probably about 4 hours. It was basically just sitting there while the tubes took the blood up, took what they need, and put the blood back in—kind of like a giant ATM machine. It was very uneventful."

— Nicole, Caregiver to Shahzad



CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

Screening Tests

Treatment to Qualify for CAR T *(If Needed)*

Collecting your T Cells—Apheresis

Bridging Therapy *(If Needed)*

Conditioning (Lympho-depleting) Chemotherapy

CAR T Cell Infusion

Weeks 1–8 After Infusion

Weeks 9–52 After Infusion

Long-term Follow-up

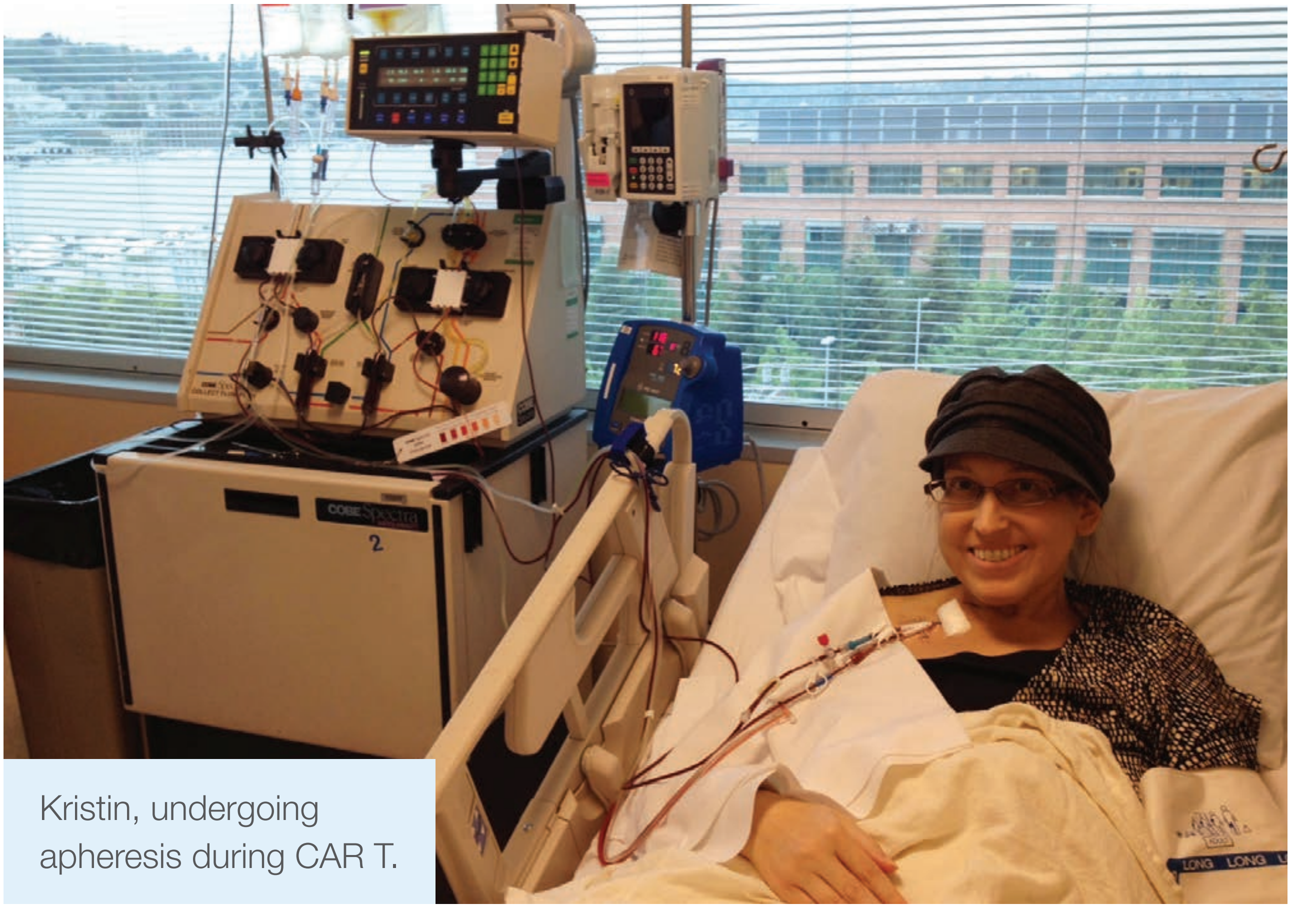
The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor's recommendation.

What is Apheresis?

Apheresis is a procedure that allows certain kinds of blood cells to be removed from the bloodstream, while the rest of the blood is returned to the patient. During apheresis, your T cells will be separated from your other blood cells so they can be sent to the lab where the "CAR" antigen will be added. The apheresis procedure takes about 4 hours, but it sometimes needs to be repeated. You may also get a temporary catheter inserted the day before apheresis and then removed the day after apheresis, so the whole process can take anywhere from 1–3 days. If you have had an auto stem cell transplant in the past, this may be familiar to you.

While you are waiting for your apheresis appointment, the treatment team will check in with you to see how you are feeling. If you are not feeling well, or if your insurer has not approved your treatment, you may need to wait a few more days or weeks before you can have apheresis.

You will need someone to drive you to and from your apheresis appointments. It is important to note that your apheresis team (the doctors and nurses that you will see during apheresis) is different from your treatment team at the CAR T center. You may not see your CAR T team during the apheresis appointment.



Kristin, undergoing apheresis during CAR T.

QUESTIONS YOU NEED ANSWERED BEFORE

Apheresis

QUESTIONS TO ASK	NOTES
☐ Will you make my appointment for apheresis? Or do I need to make it? If I need to make it, what is the contact information?	
☐ How many days should we plan to be near the treatment center for apheresis?	
☐ How long will the apheresis procedure take? Will I have 1 or 2 days of apheresis? Are there any side effects from apheresis?	
☐ Do I need to get a temporary catheter inserted before apheresis? ■ If so, when and where will that happen? When will the catheter be removed?	
☐ Will my apheresis catheter require any special care? If yes, what are the care instructions?	
☐ Are there certain foods or drinks I should have or avoid before or after apheresis?	
☐ Does my caregiver need to come with me to apheresis? Or can someone else come with me to apheresis and the catheter insertion and removal appointments?	
☐ Are there any tests that will be done before apheresis and/or insertion of my catheter? ■ If so, where and when will these be done? ■ Is there any preparation that I need to do prior to these tests?	

☐ What will my schedule look like leading up to apheresis?

☐ What should I bring with me to the apheresis appointment? Can I bring a blanket, a book, a crossword puzzle, or other items to help me feel more comfortable? Do you have Wi-Fi available at the hospital? Should I bring food or money to purchase food?

☐ If we need to spend the night, where do you suggest we stay?

☐ Do you offer financial assistance for travel and lodging? If yes, who is the contact I should work with?

- If yes, can I get the assistance in advance? Or do I need to wait to be reimbursed?

☐ How do I get a translator, if needed?

☐ Do I need approval from my insurer before apheresis and/or the temporary catheter insertion and removal?

Other questions:

GET PREPARED BEFORE

Apheresis

WHAT WE NEED TO PLAN, DECIDE, AND DO	NOTES
☐ Identify who will accompany me and help me get to my apheresis appointment.	
☐ Determine where you will stay, travel arrangements to the CAR T center, transportation to and from the center, and any parking costs.	
☐ Figure out how much will we need to spend for meals and other expenses while we are traveling.	
☐ Look into transportation, lodging, and financial assistance with your health care plan and the CAR T center.	
☐ Decide what we need friends and family to help with at home so I can get to my apheresis appointment. ■ Childcare ■ Eldercare ■ House sitting ■ Pet-sitting ■ Help with planning ■ House care (Ex: garbage collection, watering plants, mail collection)	
☐ Contact my health insurance to see if I need a pre-approval for any of the tests.	
☐ Request time off from work and talk to my employer about FMLA. Remind my caregiver to also do so, if needed.	

Other planning needs:

What Happens During Apheresis

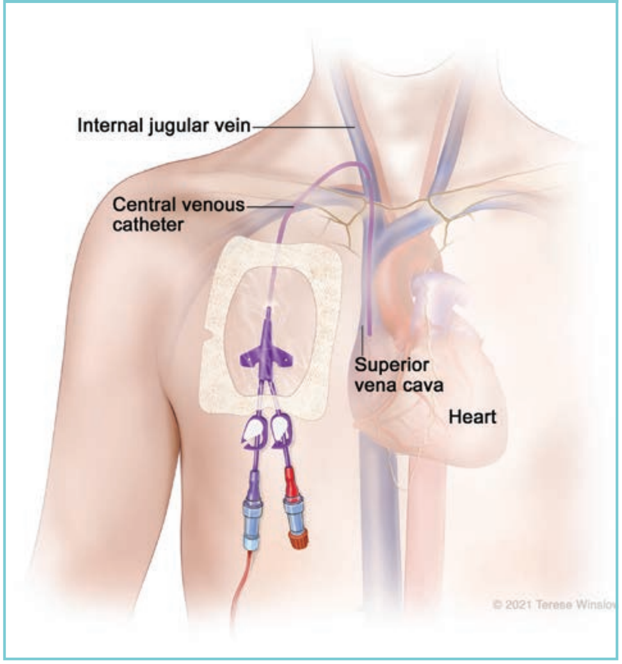
In order to get access to your T cells, the apheresis team will need to insert either a special type of catheter or 2 IV's in your arms. Even if you already have a port in place, you may need to have a different one inserted for this process. If the veins in your arms can accommodate a large needle, another option may be to have an IV put into a vein in each of your arms. If not, you may have a long flexible tube, called an apheresis catheter (a type of central venous catheter; see image to the right) put into your chest or neck. You may need to have the apheresis catheter put in during a quick procedure the day before apheresis. Dress comfortably for all of your appointments. A loose-fitting or button-down shirt will help the treatment team get to the veins in your arms.

People who have had CAR T say the catheter can feel stiff and cause pain. Talk to the nurse about any pain you are feeling and what drugs you can take to treat it.

Your IV's or catheter will be connected to an apheresis machine that will separate your T cells from your other blood cells. The T cells that are removed will be sent to the lab to be made into CAR T cells. The other parts of your blood will go back into your body. You may need a second day of apheresis if more T cells are needed. After all the T cells have been collected, the catheter or IV will be removed.

Apheresis can cause your lips or cheeks to start to feel numb or tingle. Or you may get cramps in your hands, feet, or legs. This is a side effect of losing calcium. Tell the nurse if you have these side effects. They can be treated with calcium. You can get this calcium by chewing TUMS or a generic version of TUMS (make sure the only active ingredient in the generic is calcium carbonate), or you may need it infused into your vein (IV).

CENTRAL VENOUS CATHETER



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QUESTIONS TO ASK AT
Apheresis

QUESTIONS TO ASK	NOTES
☐ Is there Wi-Fi or a laptop I can use while I am here?	
☐ When will the catheter be removed?	
☐ How long is the apheresis procedure?	
☐ How can I manage pain or discomfort because of the catheter? ■ Can I take any medications to manage it? ■ Are there care instructions for the catheter? If yes, what are they?	
☐ How will I go to the bathroom, if needed, during apheresis?	
☐ How will I know if enough T cells were collected?	
☐ Are there any side effects that may occur during or after apheresis?	
☐ Will I need to return for a second day of apheresis?	
☐ How long will it take for the lab to grow my CAR T cells and return them to the cancer center?	
☐ After apheresis, can I resume taking any medications that had to be discontinued momentarily for this procedure?	

Other questions:

After Apheresis

After apheresis, your T cells will be sent to a special lab to have the CARs added to them. This gets the T cells to grow receptors that will help them see and attack your cancer cells. It may take as little as 10–14 days or as long as 3–6 weeks for the lab to make your CAR T cells. The exact timing will depend on the type of cancer you have and specific CAR T drug you are getting. Your treatment team will call you when the cells are ready, and you can come in for the next step.

You should stay as healthy as you can while your CAR T cells are being made. You will want to:

- Wash your hands many times a day.
- Stay away from people who are sick.
- Get enough sleep.
- Eat well.
- Be as physically active as you can.
- Tell your doctor about any changes to your health.

If your cancer grows while you are waiting for your T cells to be made, you may need to get bridging chemotherapy or another type of bridging therapy. The goal of bridging therapy is to bring your cancer back under control so you can move on in your CAR T treatment. If your cancer stays under control, you can move on to conditioning chemotherapy without bridging treatment. Depending on whether you go through bridging therapy or conditioning therapy, please look at the appropriate next planning steps.

Lisa, CAR T survivor

NEXT STEP PLANNING (IF YOU NEED BRIDGING THERAPY)

If necessary, your next step may be **bridging therapy**. You can read more about bridging therapy in Chapter 11. There are 3 things you MUST do before having bridging therapy.

- ☐ Turn to the next chapter and complete what you can in the tan checklist, “My Path.”
- ☐ Next, go to page 75 and complete the blue checklist “Questions You Need Answered Before Bridging Therapy.”
- ☐ Lastly, complete the pink checklist on page 76, “Get Prepared Before Bridging Therapy.”

NEXT STEP PLANNING (IF YOU NEED CONDITIONING CHEMO)

If you do not need bridging therapy, your next step is **conditioning (lymphodepleting) chemotherapy**. You can read more about conditioning therapy by skipping ahead to Chapter 12. There are 3 things you MUST do before having conditioning therapy.

- ☐ Turn to chapter 12 and complete what you can in the tan checklist, “My Path.”
- ☐ Next, go to page 82 and complete the blue checklist “Questions You Need Answered Before Conditioning Chemotherapy.”
- ☐ Lastly, complete the pink checklist on page 84, “Get Prepared Before Conditioning Chemotherapy.”

11

Bridging Therapy *(If Needed)*

This chapter is for patients who need bridging therapy so that their cancer is under control and they are healthy enough for infusion. If you do not need bridging therapy, skip to chapter 12.

My Path

☐ The CAR T team is setting up an appointment for me to start bridging therapy.

If I don't hear back by *(date)* ____________________________, I should call *(name)*

________________________________ at *(number)* ____________________________ .

☐ I will start bridging therapy on *(date & time)* _______________________________ .

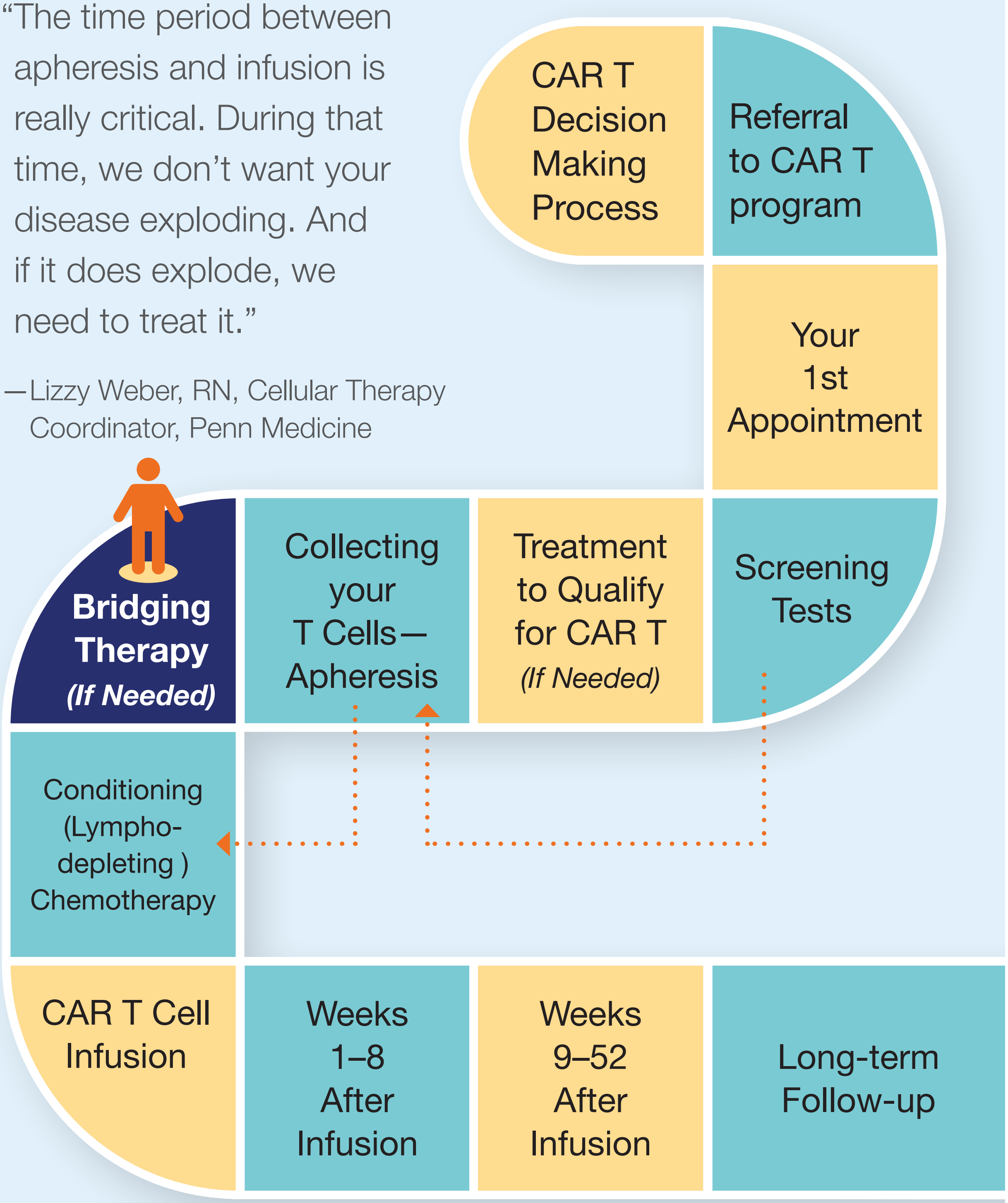
I should show up for my appointment at *(address)*__________________________ .

☐ Other ____

____

CAR T Patient Journey Map

> “The time period between apheresis and infusion is really critical. During that time, we don’t want your disease exploding. And if it does explode, we need to treat it.”
>
> —Lizzy Weber, RN, Cellular Therapy Coordinator, Penn Medicine



CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

Screening Tests

Treatment to Qualify for CAR T *(If Needed)*

Collecting your T Cells—Apheresis

Bridging Therapy *(If Needed)*

Conditioning (Lympho-depleting) Chemotherapy

CAR T Cell Infusion

Weeks 1–8 After Infusion

Weeks 9–52 After Infusion

Long-term Follow-up

The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor’s recommendation.

What is Bridging Therapy

Your cancer must continue to be controlled while you wait for your CAR T cells to be made. If your team thinks your cancer may grow aggressively while you wait, your treatment team will want to give you some type of treatment (usually chemotherapy) to get it back under control. This is called bridging therapy.

Some patients do not need bridging therapy. Others may need to be on bridging therapy for 1–3 months. Your treatment team will decide when your cancer is controlled enough for you have your CAR T cell infusion.

QUESTIONS YOU NEED ANSWERED BEFORE

Bridging Therapy

QUESTIONS TO ASK	NOTES
☐ Can I get bridging therapy from my primary oncologist, or do I need to be near the CAR T center?	
☐ If I need to come to your hospital, are you able to help me find a place to stay? Is there a social worker that I can work with? If yes, what is their contact information?	
☐ Do you have financial assistance for travel and lodging? If yes, could I receive it in advance? Or do I need to pay upfront and get reimbursed after?	
☐ Is there a financial counselor who can help me manage the costs of my treatment? If yes, what is their contact information?	
☐ How do I get a translator, if needed?	

Other questions:

GET PREPARED BEFORE

Bridging Therapy

WHAT WE NEED TO PLAN, DECIDE, AND DO	NOTES
☐ Contact my health plan to see if I need a pre-approval for any of these bridging treatment appointments.	
☐ Learn what my schedule will look like leading up to and during bridging therapy.	
☐ Identify who will accompany me and help me get to my bridging therapy appointments.	
☐ Plan where I will get bridging therapy and whether I will get it at home with my primary oncologist or if I need to make travel plans and reservations.	
☐ Look into transportation, lodging, and financial assistance, if needed.	
☐ Decide what we need friends and family to help with at home so I can get to my bridging therapy appointment and recover. ■ Childcare ■ Eldercare ■ House sitting ■ Pet-sitting ■ Help with planning ■ House care (Ex: garbage collection, watering plants, mail collection)	

Other planning issues:

It can be disappointing to learn that you have to wait 1 or more months to continue with your treatment plan. Try to keep in mind that everyone's cancer is different. Needing bridging therapy does not mean that you have "failed." It also doesn't mean CAR T won't work as well. It just means that this is what is happening with your cancer right now—and this is what needs to be done to treat it.

QUESTIONS TO ASK AT
Bridging Therapy

QUESTIONS TO ASK	NOTES
☐ What kind of bridging therapy do I need to get?	
☐ What will be the schedule for this therapy? And for how long?	
☐ What are the side effects of this therapy?	
☐ How will you monitor to see if bridging therapy is working?	
☐ If I have questions during bridging therapy, who should I contact? What is their contact information?	
☐ How will I be notified if bridging therapy is successful and I am eligible for CAR T?	

Other questions:

SIDE EFFECTS

If you need to have bridging therapy, you may:

- Have side effects like nausea, vomiting, and dehydration
- Start to feel worse before you feel better
- Feel sad, disappointed, discouraged, or angry that you have to wait longer than you thought you would to have your CAR T cell infusion

NEXT STEP PLANNING

Your next step is **conditioning (lymphodepleting) chemotherapy**. You can read more about conditioning therapy in Chapter 12. There are 3 things you MUST do before having conditioning therapy.

☐ Turn to chapter 12 and complete what you can in the tan checklist, “My Path.”

☐ Next, go to page 82 and complete the blue checklist “Questions You Need Answered Before Conditioning Chemotherapy.”

☐ Lastly, complete the pink checklist on page 84, “Get Prepared Before Conditioning Chemotherapy.”

12

Conditioning (Lymphodepleting) Chemotherapy

My Path

Once your bridging therapy is complete, the CAR T team will be able to tell you if you are back on track to receive conditioning chemotherapy and infusion.

☐ Bridging therapy has not brought my cancer back under control enough to move on to infusion. Here are the next steps my team suggests ______________

____

____ .

If you need more bridging therapy, you can download this book and print a blank version of chapter 11 to help you plan for your next therapy at www.CancerSupportCommunity.org/CART.

☐ The CAR T team is setting up an appointment for me to have conditioning chemotherapy. If I don't hear back by *(date)* ____________________, I should call *(name)* ________________________________ at *(number)* _____________________ .

☐ I will start conditioning chemotherapy appointment on *(date & time)* __________

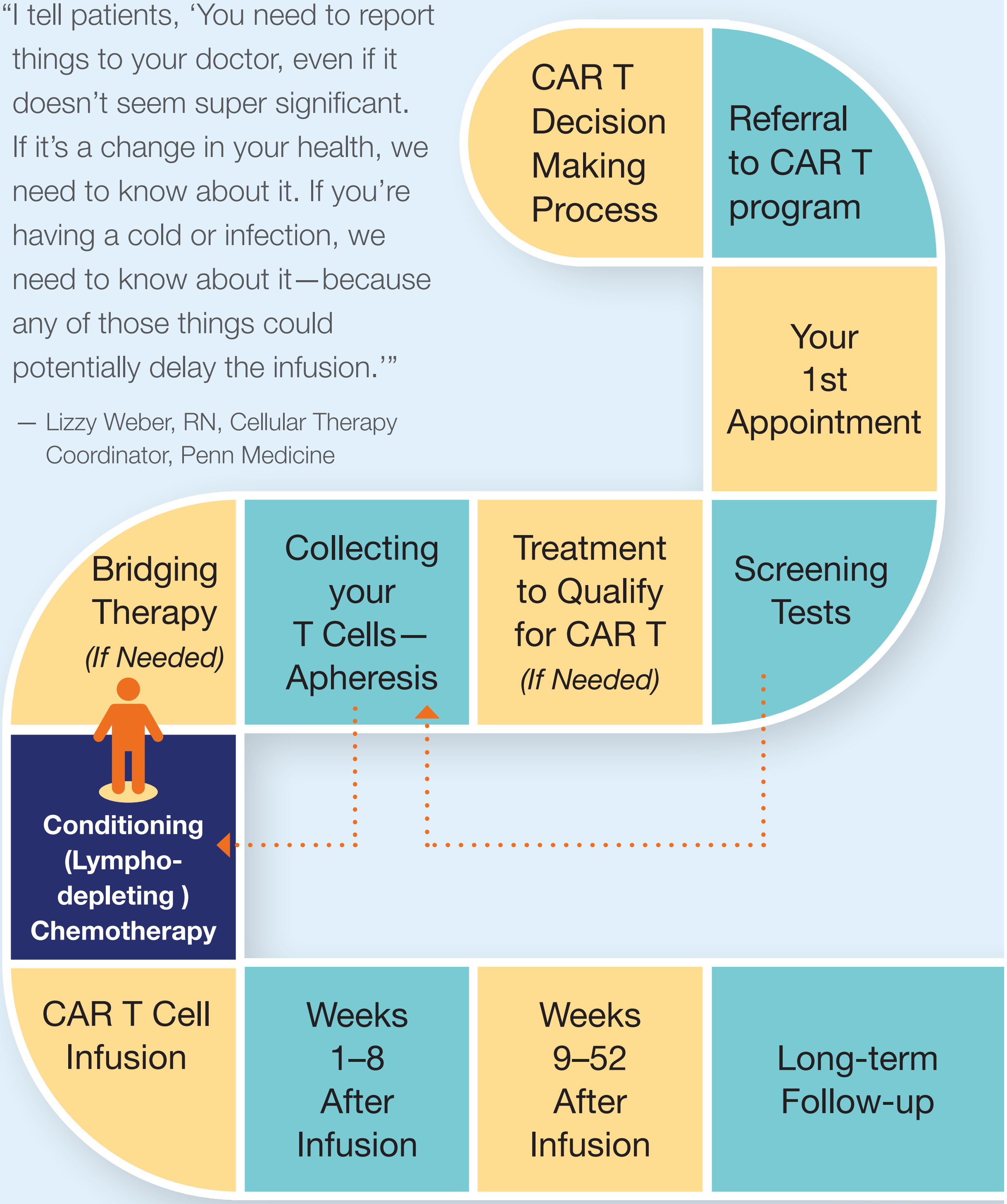
____ .

☐ I should show up for my appointment at *(address)* _________________________ .

CAR T Patient Journey Map

“I tell patients, ‘You need to report things to your doctor, even if it doesn’t seem super significant. If it’s a change in your health, we need to know about it. If you’re having a cold or infection, we need to know about it—because any of those things could potentially delay the infusion.’”

— Lizzy Weber, RN, Cellular Therapy Coordinator, Penn Medicine



CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

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Bridging Therapy *(If Needed)*

Conditioning (Lympho-depleting) Chemotherapy

CAR T Cell Infusion

Weeks 1–8 After Infusion

Weeks 9–52 After Infusion

Long-term Follow-up

The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor’s recommendation.

What is Conditioning Chemotherapy?

You will be given conditioning chemotherapy (also called lymphodepleting chemotherapy) before you receive your CAR T cell infusion. This is not the same as bridging therapy. This is a low-dose chemotherapy that is given to make space for the new CAR T cells.

Each person's experience and timeline for conditioning chemotherapy will be different. Your CAR T doctor will let you know how many days of conditioning chemotherapy and rest you will need before the CAR T infusion. This is what the process will look like leading up to the CAR T infusion:

Most patients get conditioning chemotherapy from their CAR T treatment team. Some may get it from their primary oncologist. Since you will probably need to be near the CAR T program for conditioning chemotherapy, you should plan travel logistics for conditioning chemotherapy and infusion at the same time because they happen one after the other.

Most patients do not stay in the hospital while getting conditioning chemotherapy. Talk to your CAR T team about the best place for you to stay while being treated.

QUESTIONS YOU NEED ANSWERED BEFORE

Conditioning Chemotherapy

QUESTIONS TO ASK	NOTES
☐ What should I bring with me to the conditioning chemotherapy appointments?	
☐ What will my schedule look like leading up to and during conditioning chemotherapy?	
☐ For how many days will I be receiving conditioning chemotherapy? What is the length of each conditioning chemotherapy treatment?	
☐ How many rest days will I have in between conditioning chemotherapy and CAR T infusion?	
☐ What type of conditioning chemo will I be receiving?	
☐ How does this conditioning chemotherapy differ from chemotherapy I've had before?	
☐ Will I get instructions about how much water to drink daily?	
☐ Will I need to come in to get fluids through a vein (IV)?	
☐ Does my caregiver need to be with me for each conditioning chemotherapy appointment?	
☐ Do you have financial assistance for travel and lodging? If yes, could I receive it in advance? Or do I need to pay upfront and get reimbursed after?	

☐ If we stay in a hotel, how can we get to the CAR T center for chemotherapy? Are there shuttles or transportation vouchers?	
☐ Is there a financial counselor who can help me manage the costs? If yes, what is their contact information?	
☐ How do I get a translator, if needed?	

Other questions:

GET PREPARED BEFORE

Conditioning Chemotherapy

WHAT WE NEED TO PLAN, DECIDE, AND DO	NOTES
☐ Contact my health insurance to see if I need a pre-approval for any of these treatments.	
☐ Identify who will come with me and help me get to my conditioning chemotherapy appointments?	
☐ Determine where we will stay, travel arrangements to the CAR T center, transportation to and from the center, and any parking costs.	
☐ Determine how much will we need to spend for meals and other expenses while we are traveling.	
☐ Look into transportation, lodging, and financial assistance, if needed.	
☐ Decide what do we need friends and family to help with at home so I can get to my conditioning chemo. ■ Childcare ■ Eldercare ■ House sitting ■ Pet-sitting ■ Help with planning ■ House care (Ex: garbage collection, watering plants, mail collection)	
☐ Request time off from work and talk to my employer about FMLA. Remind my caregiver to also do so, if needed.	

☐ Look into disability benefits if I haven’t already done so.	
☐ Determine who my caregiver can turn to for support.	

Other planning issues:

The chemotherapy drugs usually used are cyclophosphamide (Cytoxan) and fludarabine (Fludara). Depending on your cancer diagnosis and the specific CAR T approach being taken, different medications may be used. Your CAR T team will ultimately decide what is appropriate in your case. Each chemotherapy appointment will take from 4–6 hours. The most common side effects are:

- Feeling tired
- Nausea
- Vomiting
- Constipation or diarrhea
- Lack of appetite or taste changes
- Headache

Your treatment team can give you anti-nausea medication before your chemotherapy treatments and anti-nausea pills that you can take at home. If you wear contacts, bring glasses with you because chemotherapy can cause your eyes to feel dry.

You will be asked to drink a lot of water on the days you have low dose chemotherapy and on your days of rest. Your doctor may also want you to come to the hospital to get fluids through a vein (IV). Try to remain as active as you can throughout chemotherapy. Take walks around the hospital, sit up at your table for meals, and engage with your friends and family. If you are feeling dizzy, weak, or confused, walk with a caregiver.

After chemotherapy and rest, you will receive your CAR T infusion. If you begin to get sick or if you get an infection, your doctors will need to delay your CAR T infusion until you are feeling better. It can be stressful to learn that you need to wait longer to get your treatment. If this is needed, know that this is what is best for you right now.

QUESTIONS TO ASK AT

Conditioning Chemotherapy

QUESTIONS TO ASK	NOTES
☐ Will I get anti-nausea drugs while I'm on conditioning chemotherapy?	
☐ Are there any other possible side effects from the conditioning chemotherapy?	

Other questions:

NEXT STEP PLANNING

Your next step will be to have **CAR T cell infusion**. You can read more about CAR T cell infusion in Chapter 13. There are 3 things you MUST do before having CAR T cell infusion.

☐ Turn to the next chapter and complete what you can in the tan checklist "My Path."

☐ Next, go to page 89 and complete the blue checklist, "Questions You Need Answered Before CAR T Cell Infusion."

☐ Lastly, complete the pink checklist on page 91, "Get Prepared Before CAR T Cell Infusion."

13

CAR T Cell Infusion

My Path

You must be at the CAR T center for infusion. You also need to be within 30–60 minutes of the CAR T center with a 24/7 caregiver for at least 4 weeks after infusion.

☐ The CAR T team is setting up an infusion appointment for me. If I don't hear back by *(date)* ______________, I should call *(name)* ______________________ at *(number)* ____ .

☐ My infusion appointment is set for *(date & time)* ________________________ .
I should show up for my appointment at *(address)* ________________________
____ .

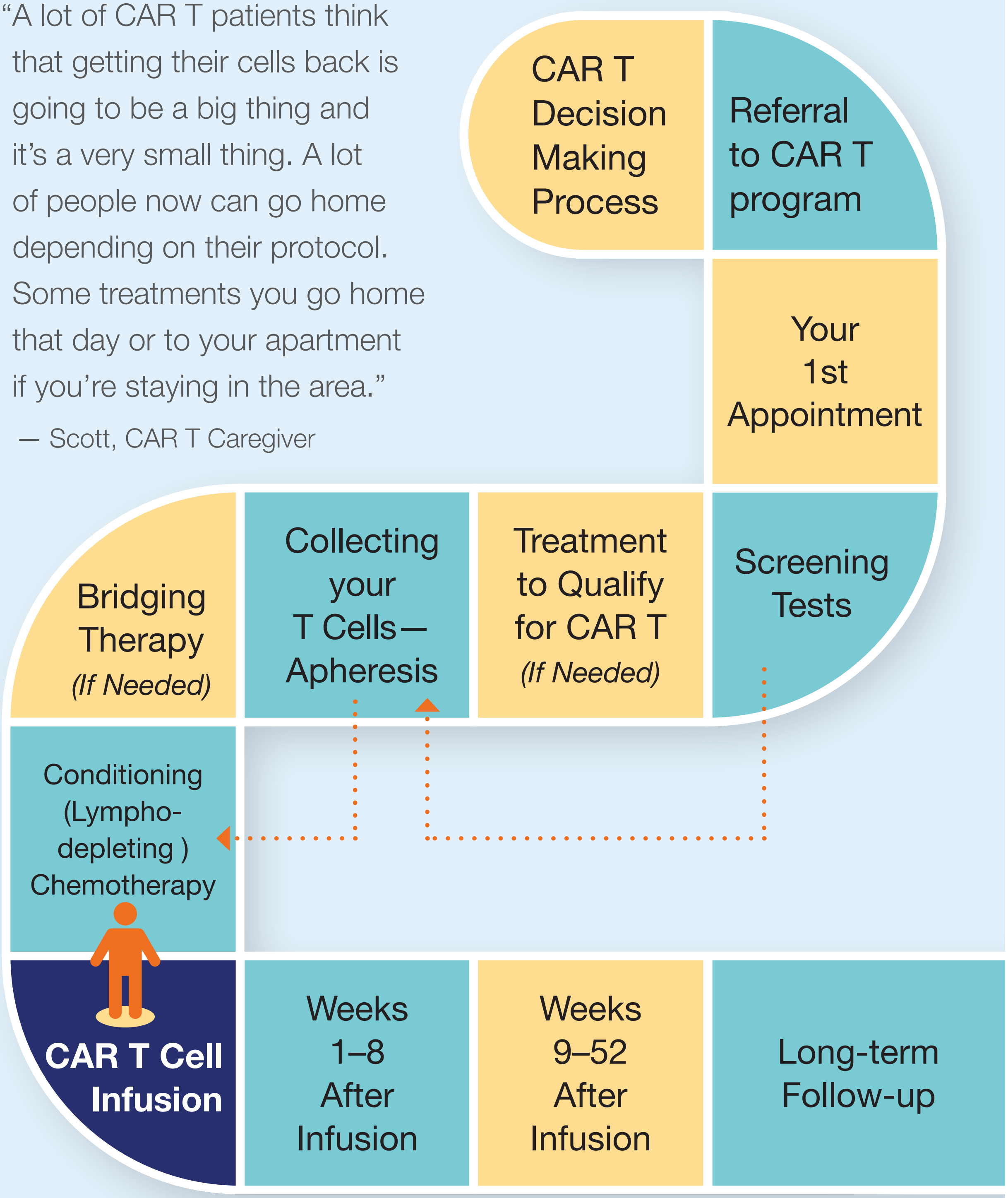
☐ I will stay in the hospital after my infusion for at least __________ days/weeks.

☐ I will be an outpatient. I will stay at *(address)* ___________________________ .

☐ Other ____

CAR T Patient Journey Map

> "A lot of CAR T patients think that getting their cells back is going to be a big thing and it's a very small thing. A lot of people now can go home depending on their protocol. Some treatments you go home that day or to your apartment if you're staying in the area."
>
> — Scott, CAR T Caregiver



CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

Screening Tests

Treatment to Qualify for CAR T *(If Needed)*

Collecting your T Cells— Apheresis

Bridging Therapy *(If Needed)*

Conditioning (Lympho-depleting) Chemotherapy

CAR T Cell Infusion

Weeks 1–8 After Infusion

Weeks 9–52 After Infusion

Long-term Follow-up

The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor's recommendation.

The CAR T cell infusion is when your new CAR T cells are put into your body. Some CAR T patients check into the hospital for their CAR T infusion and don’t check out again for several weeks. Some CAR T patients can be treated as outpatient. This means you can go home—or to the place you are staying near the hospital—after your infusion. If that is the case, you must stay in a place where you can get to the hospital by car in 30 minutes or less. Some hospitals allow you to be 60 minutes away.

QUESTIONS YOU NEED ANSWERED BEFORE THIS STEP:

CAR T Cell Infusion

QUESTIONS TO ASK	NOTES
☐ When do I need to check in?	
☐ What will my schedule look like leading up to CAR T infusion?	
☐ How long will my CAR T infusion appointment take?	
☐ What can I expect to happen during my CAR T infusion?	
☐ What should I bring with me to infusion? Is there anything I shouldn’t bring?	
☐ Can I bring a blanket, flowers, reading materials, and other personal items with me?	
☐ As an inpatient, will there be sleeping arrangements for my caregiver onsite?	
☐ As an outpatient, what should I have at home or where I am staying?	

☐ As an outpatient, how much travel time can I have between the place I am staying and the hospital? 30 minutes or less? 60 minutes or less?	
☐ Can I bring other family and friends to my CAR T infusion appointment?	
☐ What will my caregiver need to do during infusion?	
☐ Who can my caregiver turn to for support?	
☐ Do you have financial assistance for travel and lodging? If yes, could I receive it in advance? Or do I need to pay upfront and get reimbursed after?	
☐ If we stay in a hotel, how can we get to the CAR T center for infusion? Are there shuttles or transportation vouchers? If I drive, where is parking and can I be reimbursed for any parking costs?	
☐ How do I get a translator, if needed?	
☐ What side effects should my caregiver look for after the infusion?	

Other questions:

GET PREPARED BEFORE

CAR T Cell Infusion

WHAT WE NEED TO PLAN, DECIDE, AND DO	NOTES
☐ Identify who will come with me to my CAR T infusion appointment.	
☐ If I am an outpatient, determine where will we stay for the 4 or more weeks that we need to be near the CAR T center. If I am an inpatient, determine where will my caregiver stay.	
☐ Calculate our budget for our overall living costs in the 4–8 weeks after infusion.	
☐ Figure out where my caregiver and I will stay after I check out of the hospital after CAR T infusion and before we can go home at the end of 4–8 weeks?	
☐ If we are not already near the CAR T center, plan for getting to the center for the CAR T infusion: ■ Will we need to make reservations to fly, take a train, taxi or rideshare? ■ How much are those costs? ■ Can we drive there? ■ How much and where is parking?	
☐ Plan how much will we need to spend for meals and other expenses during these weeks. Figure out where we can get groceries and if the place we are staying at has a kitchen so we can cook.	
☐ Identify what transportation mode will we use in the weeks after CAR T infusion.	

☐ Look into transportation, lodging, and financial assistance. Work with a social worker for assistance.

☐ Decide what do we need friends and family to help with at home so I can stay near the CAR T center for these few weeks.
  - Childcare
  - Eldercare
  - House sitting
  - Pet-sitting
  - Help with planning
  - House care (Ex: garbage collection, watering plants, mail collection)

☐ Contact my health plan to see if I need a pre-approval for any of these appointments.

☐ Request time off from work and talk to my employer about FMLA. Remind my caregiver to also do so, if needed.

☐ Look into disability benefits if I haven’t already done so. Work with social worker for assistance.

☐ Identify who can my caregiver turn to for support after infusion.

Other planning issues:

TIP

- Find people your caregiver can turn to for support after your CAR T infusion.
- Let your family and friends know that if you have side effects, they may not be able to visit you in the hospital for 1–2 weeks.

What to Expect: Inpatient Infusion

If you are inpatient, you should plan to be in the hospital for at least 1 week or more. Pack a bag in advance with some of the things you will need to be comfortable during your stay, such as:

- Day and night clothes; disposable underwear
- Cell phone and charger
- Laptop or tablet and charger
- Snacks
- Music, crossword puzzles, cards, board games, and other things for you to do at the hospital (as allowed by treatment center)
- Any personal items to make you more comfortable (photos, cards, favorite pillow or blanket, preferred toiletries, and so forth)
- Insurance cards
- Butterscotch candies (to help with the metallic taste you get during infusion)

If you develop side effects, you may need to stay in the hospital longer. Your treatment team will let you know when you can leave the hospital. When you leave, you will still need to be with your caregiver 24/7. You also will need to stay near the CAR T center for at least 1 month after infusion. You can stay at a hotel or other housing option. If you develop side effects, you may need to check into the hospital again.

What to Expect: Outpatient Infusion

If you are outpatient, you can leave the hospital after the CAR T infusion. You will still need to be with your caregiver 24/7 and be near the CAR T center for at least one month. You can stay at a hotel or other housing option. Your treatment team will have you come back to the CAR T center several times in the first week after infusion to see how you are doing.

If you start to have any side effects, you will need to call your treatment team and go to the CAR T center right away. You should not go to the emergency room at a different hospital because they may not know how to treat your CAR T cell therapy side effects. If you need to go to an emergency room at a different hospital, make sure you and your caregiver have a copy of your wallet card for CAR T and share it with the emergency room hospital staff.

Infusion Day

You might be asked to check in for your infusion either the night before or the morning of the infusion. Dress comfortably for your infusion appointment. Your treatment team will need to access the veins in your arm and/or neck, so try to wear a loose-fitting or button-down shirt.

Before you get your CAR T cells, to prevent an infusion reaction, you will be given Tylenol, Benadryl, and fluids. The CAR T cells will be put into your body through a vein (IV). This will take about 30 minutes. During the procedure, your vitals will be monitored.

TO STAY HEALTHY BEFORE YOUR INFUSION

- Wash your hands with soap for 20 seconds, or as long as it takes to sing the “Happy Birthday” song. Be sure to wash your hands before eating and after using the bathroom.
- Stay away from people who are sick.
- Use a soft toothbrush.
- Don’t do anything that may cause you to get hurt or bleed.
- Drink 2–3 quarts or 8–12 cups of water a day.
- Eat a healthy diet.
- Use lip balm to keep your lips moist.
- Do not use over the counter medications, herbs, or supplements without talking to your CAR T team first.
- Use sunscreen when outside.
- Let your CAR T team know if you are anxious or have any concerns about the treatment.

QUESTIONS TO ASK AT THIS STEP:

CAR T Cell Infusion

QUESTIONS TO ASK	NOTES
☐ Who do I contact if I have side effects after the CAR T infusion? Do I need to admit myself to the hospital if I experience side effects (ex. fever, body chills, muscle aches, etc.)?	
☐ What is my schedule after the infusion?	
☐ When is my next appointment with you?	

Other questions:

NEXT STEP PLANNING

Your next step will be monitoring side effects for **weeks 1–8 after the infusion**. You can read more about what happens after infusion in Chapter 14. There are 3 things you MUST do before your infusion is complete so that you are prepared for the post-infusion period.

☐ Turn to the next chapter and complete what you can in the tan checklist, “My Path.”

☐ Next, go to page 107 and complete the blue checklist, “Questions You Need Answered Before Weeks 1–8 After Infusion.”

☐ Lastly, complete the pink checklist on page 109, “Get Prepared Before Weeks 1–8 After Infusion.”

14

Weeks 1–8 After Infusion

My Path

☐ I will remain in the hospital for at least ___________ days.

☐ I need to remain close to the hospital and with my caregiver for the next ___________ days.

☐ I will be staying at *(location)* ____ .

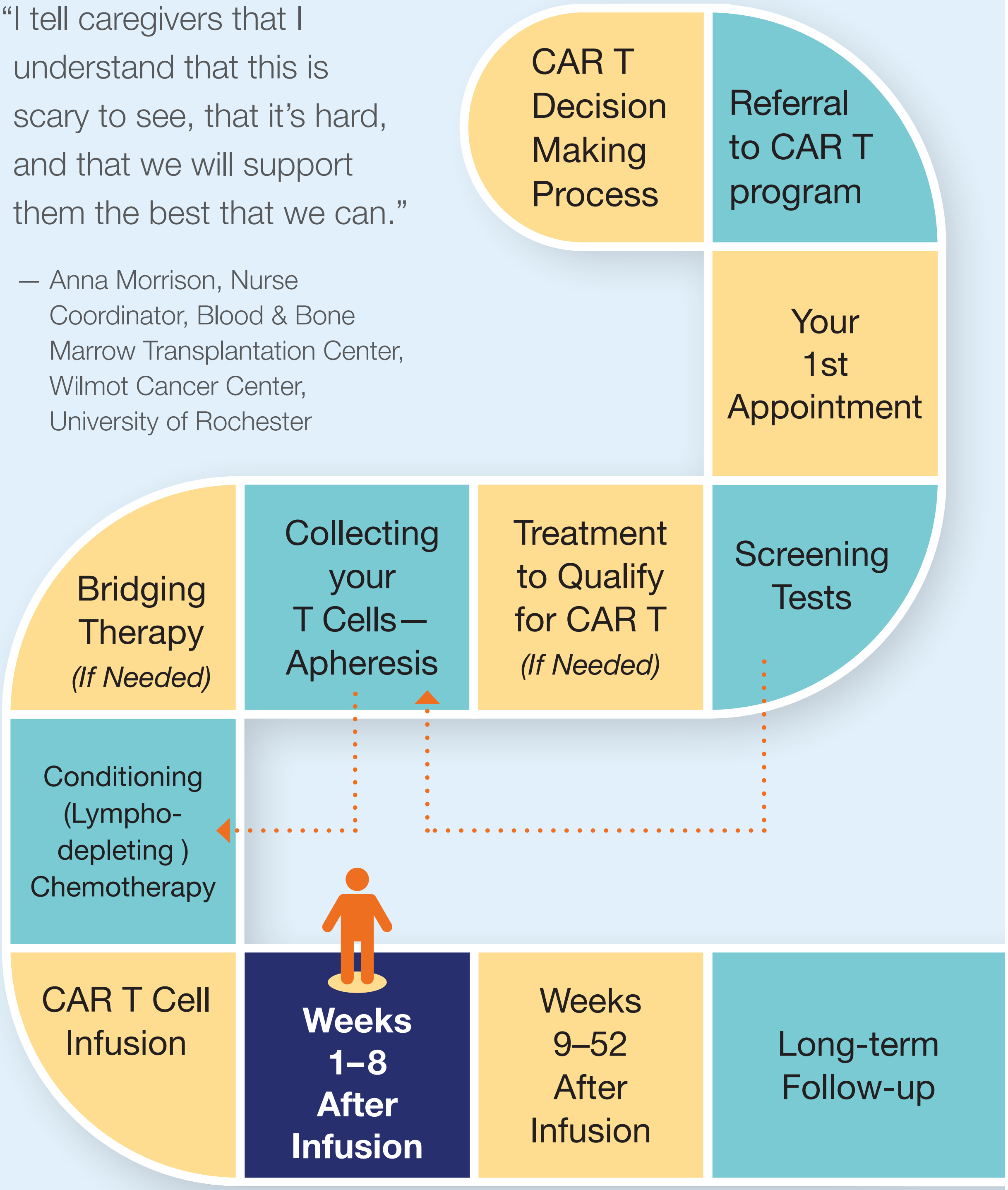
☐ My next appointments are scheduled for *(dates)*:

- ____
- ____
- ____

☐ Other ____

CAR T Patient Journey Map

> "I tell caregivers that I understand that this is scary to see, that it's hard, and that we will support them the best that we can."
>
> — Anna Morrison, Nurse Coordinator, Blood & Bone Marrow Transplantation Center, Wilmot Cancer Center, University of Rochester



The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor's recommendation.

The CAR T infusion can cause side effects. For at least 4 weeks after the infusion, you will need to be within 30–60 minutes of the CAR T center. You will also need to be monitored closely and should have your caregiver with you 24/7. See Section 3, page 172 for worksheets to help you keep track of your side effects. You will continue to need caregiver support up to 8 weeks after the CAR T infusion. After 8 weeks, your doctor will usually let you know that you can restart some of your regular daily activities like driving and using heavy machinery, or going back to work.

For more information on how to manage side effects, take a look at our information on how to manage side effects including our **website** and our book on ***Coping with Side Effects***.

Your CAR T cells can start killing your cancer cells as soon as they are put into your body. This can cause two main types of side effects: cytokine release syndrome (CRS) and neurotoxicity. About 80% of CAR T patients have some side effects that fall into these two categories. Some patients get severe side effects, while others get mild or no side effects. If you get severe side effects, it does not necessarily mean the treatment is working. If you get mild side effects, it does not necessarily mean the treatment is not working. Whether you have side effects or not does not predict whether CAR T is really working for you. Watch our **videos** to hear CAR T survivors and their caregivers tell their stories about having mild symptoms or severe symptoms and CAR T still working.

> “I was not prepared for what my wife displayed while going through this process. I was a wreck. I never imagined my wife not knowing who I am. I thought I was losing my wife. I really did. They told me ahead of time I was going to see things that I was not prepared for, but I had no idea that it was going to be like that. She would be rocking in the bed. Her legs would be going all over the place. She doesn’t remember any of this. It was a very traumatic experience.”
>
> —Dave, Caregiver to wife, Maxine

Side Effects to Look For

Your caregiver has probably seen you manage side effects from other cancer treatments. But there are some neurological (brain) side effects that CAR T can cause that they have not seen before. You may also develop a high fever, which can cause you to become confused or delirious.

Before your infusion, your caregiver should talk to your nurse about the neurological side effects that you might have and what they can do in the hospital if you have them. This can include:

- Keeping the lights low
- Talking calmly
- Comforting music
- Telling stories about happy things

It may be difficult for your caregiver to watch you have extreme side effects. See page 126 of Section 3 for support resources that your caregiver can use. Your caregiver should keep track of your side effects and share any concerns with the CAR T team immediately.

CYTOKINE RELEASE SYNDROME (CRS)

Your new CAR T cells will start working in your immune system right away. This can cause your immune system to go into overdrive and release molecules called cytokines. If your immune system releases a lot of cytokines, you may develop flu-like symptoms, such as:

- Fever
- Tiredness
- Muscle aches and pains

> “As a caregiver, it’s difficult to watch your loved one be sick and spike a fever. All they want to do is crawl into bed and put a blanket over their head and just sleep. The last thing they want to do is get out of bed and go to the hospital. So, for a caregiver, that's a big part of your responsibility is to be there for the patient and to motivate them to get up and go to the hospital. I feel really bad for the patient as all they want to do when they spike a fever is lay in bed and rest, especially if they've had lots and lots of prior treatments.”
>
> — Benny, Caregiver to Kristin

You may also have:

- Low blood pressure
- Dizziness
- Shortness of breath
- Increased heart rate
- Less urine than normal
- Body chills
- Night sweats
- Abnormal liver function
- Blood clots

NEUROLOGICAL TOXICITIES (BRAIN SIDE EFFECTS, ALSO CALLED NEUROTOXICITIES)

Cytokines can also affect your brain and nervous system, which can cause another side effect known as "neurological toxicities" or "neurotoxicities." You may not know or remember that you are having the symptoms of this side effect, but they can be very scary for your caregiver.

Neurological toxicity can cause symptoms such as:

- Anxiety
- Sleepiness
- Confusion
- Difficulty walking
- Facial droop
- Seeing things that aren't there (hallucinations)
- Problems finding the right words
- Seizures
- Infection
- Headache
- Being unresponsive (coma)

In addition to cytokine release syndrome and neurotoxicity, there are other side effects you may experience.

TUMOR LYSIS SYNDROME

Tumor lysis syndrome (TLS) is a condition that happens when cancer cells breakdown quickly, releasing chemicals into the blood. If your kidneys cannot remove these chemicals fast enough, you can develop this condition.

CYTOPENIA (LOW BLOOD COUNT)

Another common side effect is prolonged low blood counts (cytopenias). This is common the first few weeks due to the effects of conditioning (lymphodepleting) chemotherapy. However, you may have this for a longer period of time, which would become more obvious in the first 4–8 weeks after infusion. Developing cytopenia increases your risk of infection.

B CELL APLASIA

In most cases, the CAR T drug also attacks normal, healthy B cells, which causes B cell aplasia (low number of B cells). This makes it harder for your body to fight germs and can increase your risk of infection. To treat this side effect, you may need intravenous immunoglobulin infusions, also known as IVIG. This is only expected to occur in cancers that form in B cells, like myeloma and certain types of leukemias and lymphomas. B cell aplasia may first appear in the first 8 weeks after infusion.

Responding to Side Effects

It is important to remember that every patient's experience is unique. Not everyone will have side effects. Side effects will look different from person to person. Side effects may show up sooner for some patients and later for others. Ask your care team what is common for your cancer type and your drug type.

For most patients that get side effects, CRS happens first. Then, about 24–48 hours after CRS, you may start to have signs of neurotoxicity. CRS and neurotoxicity can start within hours of the infusion and often lasts for 3–4 days. Technically, they can develop at any time after your CAR T cell therapy, but it is not common for them to develop more than 3 weeks after the CAR T cell infusion. That is why you need to remain close to the cancer center for 4 weeks after your CAR T cell infusion. For most cancer centers, "close" means you can get there in 30 minutes or less.

An emergency room at another hospital may not be prepared to treat CAR T cell therapy symptoms. If you do have to go to another hospital, show them the wallet card you were given that provides information on how to contact your CAR T team. Take a picture of your wallet card, so you always can just show a new health care provider your phone.

IF YOU ARE AN OUTPATIENT:

A fever is usually the first symptom of CRS. If you develop a fever, you will need to be admitted to the cancer center where you are being treated.

If you have any of these symptoms, you should tell your CAR T team right away. You will be given medication to treat these symptoms. This is usually tocilizumab (Actemra®) or a steroid. Your CAR T team may advise you not to take drugs like Tylenol (acetaminophen) or Advil (ibuprofen). These medications can lower your temperature and might make it harder for your doctor to know if you have an infection. Tocilizumab prevents the cytokines from hurting your heart, kidneys, liver, or lungs. You may need to receive blood and platelets to treat your side effects. If you have a lot of symptoms, you may need to be admitted to the intensive care unit (ICU). Treating your side effects will not make the CAR T cell therapy less effective.

It is important to remember that the symptoms of CRS and neurotoxicity are usually temporary and reversible. However, in rare cases, some side effects are long lasting or may lead to death. You and your caregiver should talk to your doctor about what side effects you can expect and how you should respond.

> "The medicines that we use to reverse cytokine release syndrome do not impair the activity of the CAR T cells themselves."
>
> — Dr. Jeremy Abramson, Director,
> Lymphoma Program,
> Massachusetts General Hospital

Is It An Emergency?

Your caregiver should call your CAR T team right away if you have any of the below side effects:

- A temperature above 100.4 degrees
- Chills or shivering
- Confusion
- Dizziness
- A fast or strange heartbeat
- Extreme tiredness or weakness
- Pain, redness, swelling, or warmth in your arm or leg
- Nausea and vomiting
- No appetite for several days
- Sores or white spots in your mouth
- Constipation or diarrhea for more than one day
- Bruises or small red spots under your skin
- Bleeding
- A feeling of pain when you urinate or the need to go often
- A cough that doesn't go away
- New pain

If this happens, my caregiver will call:

Name ____

Phone Number ______________________________________

Your caregiver should call 911 if you have:

- Chest pain
- Shortness of breath
- Trouble breathing
- A very bad headache that does not go away
- Trouble seeing
- Bleeding that does not stop or slow down after several minutes.

Be sure to mention that you are a CAR T patient when you or your caregiver call 911 or visit an emergency room for symptoms. Show your wallet card if you need emergency care, urgent care, or are seeing a new provider. Take a picture of your wallet card on your phone so you can easily take it with you.

TIP: Take a picture of your wallet card, so you always have the picture in your phone to show a new health care provider. You can also enter your personal emergency contacts and medical contacts into the Emergency app on your phone and/or medical conditions on your Health information phone app.

This page was intentionally left blank so you & your caregiver can keep this page as a reference.

Because CAR T can weaken your immune system, you will want to take special precautions to avoid infections after infusion. Carry a safety supply bag with you that includes gloves, masks, hand sanitizer, disinfectant, and baby wipes so you can be ready for any situation.

Some general guidelines on preventing infections include:

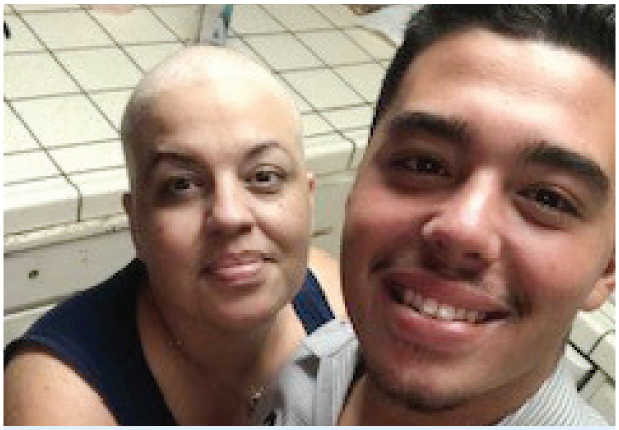
- Washing your hands regularly, for 20 seconds or as long as it takes to sing the "Happy Birthday" song
- Practicing food safety
  - Wash your hands before eating
  - Wash or rinse fruits and vegetables
  - Avoid sharing utensils and drinking containers
  - Avoid eating raw meats and unpasteurized milk or juices
- Not cleaning up after pets – ask your loved ones for help
- Avoiding large crowds
- Practicing good oral hygiene – brush your teeth twice a day with a soft toothbrush and floss
- Showering daily and washing any areas that could harbor bacteria (feet, groin, armpits, and other moist areas)
- Making sure all family members and visitors thoroughly wash their hands before entering your home or room
- Avoiding people who have or have signs of a cold, flu, or any other contagious disease. If a family member has a cold or infection they should ideally stay with a friend or family member while they are sick. However, if that isn't possible, they should wear a mask in your home.

> "If you don't get sick it doesn't mean that the treatment is not working as well as it does in people who do get sick. Right now, I have three patients who…are in complete remission. One was never in the hospital and never got sick. One had only a fever. And one had many side effects."
>
> —Dr. Stephen Schuster, Director of the Lymphoma Program, Penn Medicine

Caring for the Caregiver

Caring for a loved one undergoing CAR T is wholly consuming and requires your caregiver's full attention. Caregivers play a very important role all through the CAR T process, and most especially in the weeks following the CAR T infusion. Not only do you need your caregiver with you during your different appointments, but in the first 8 weeks after the CAR T infusion, your caregiver plays a critical role in identifying and responding to your side effects. During this time, caregivers may feel overwhelmed, stressed, and exhausted. It is completely normal and valid for caregivers to feel this way.

Because of the important role they play, caregivers need to make sure they remain physically, mentally, and emotionally healthy. It is important for caregivers to have their own care plan and understand their needs. What helps them get through bad days? What helps them relax? Do they have any health concerns they need to pay attention to? What are they doing to stay healthy? Are movies or books an escape? How can friends and family support them?



Lisa, CAR T survivor, with her son, Nicolas.

Some of the practical tips that CAR T caregivers have shared on how to care for yourself include:

- When your loved one is in treatment or at appointments, use that time for yourself. Go on a walk. Read a book. Get some fresh air. Do something for yourself.
- So many CAR T caregivers emphasize the importance of having a support system. Reach out to your network, communicate with your friends and family when you are having a hard time. Identify those in your network who can help you with everyday tasks like cooking, cleaning, helping with kids, and running errands.
- Find ways to distract yourself. Talking to others, even if they cannot fully understand the CAR T process, it can still be distracting and therapeutic.
- If you are able to, find support groups to help you cope with the process.
- It is important to communicate with the nurses and the doctors. They will tell you what is going on, help explain the situation, and explain the treatments. Do not be afraid to ask questions. The doctors and nurses are there for you as well as the patient.

The most important thing for caregivers to remember is that they also have needs and they should find ways to take care of their needs. Caregivers should read about the CAR T journey ahead of time so they are prepared for all the steps, but also so they can prepare for what they need.

QUESTIONS YOU NEED ANSWERED BEFORE

Weeks 1–8 After Infusion

QUESTIONS TO ASK	NOTES
☐ What side effects should my caregiver and I look for? Do you have a list of side effects that we can take with us? How long can these side effects take place?	
☐ Are there any tests that my caregiver should know about (ex: having a temperature above a certain number, the ability to answer specific questions)	
☐ Who should be our 1st contact person if we detect a side effect? What is their contact information (name and phone number)?	
☐ Who should we contact after hours? What is their contact information (name and phone number)?	
☐ What side effects require hospital admission?	
☐ For what reasons should we call 911 instead of the CAR T treatment team?	
☐ How can I avoid infections?	
☐ How often will I need to return to the CAR T center in the first month after infusion for check-ups?	
☐ How do I schedule my check-up appointments? Is there an assigned scheduler to work with? If yes, what is their contact information?	

☐ What should I bring with me to these check-up appointments?	
☐ Are there any reasons that would require us to extend our stay near or at the CAR T center past 4 weeks?	
☐ What support is available for my caregiver as I am experiencing side effects?	■ CSC’s Cancer Support Helpline: 844-792-6517 ■ **MyLifeLine** Discussion Board

Other questions:

GET PREPARED BEFORE

Weeks 1–8 After Infusion

WHAT WE NEED TO PLAN, DECIDE, AND DO	NOTES
PLANNING AFTER INFUSION FOR OUTPATIENTS	
☐ Ensure my caregiver understands what side effects to look out for.	
☐ Confirm my caregiver understands who to call at all times of the day if we notice a side effect.	
☐ Verify my caregiver understands when a side effect requires hospital admission.	
☐ Figure out my plan for getting to the CAR T center or hospital if side effects arise. Do we need to take a shuttle, taxi or rideshare? Can we drive there? How much and where is parking?	
☐ Take a picture of your wallet card to show new health care providers if you experience side effects. Emergency contacts, medical team contacts and personal health information can also be entered and used on your phone apps.	
PLANNING AFTER INFUSION FOR EVERYONE	
☐ Identify who my caregiver can turn to for support after the CAR T infusion.	
☐ My caregiver should re-read information and re-watch videos about CAR T side effects to be reminded that even very severe side effects can be managed.	

Once you are out of the hospital, you should keep a bag ready with everything you will need if you need to go to the hospital due to a side effect. Here are some ideas of what to keep with you in your “go-bag”:

- Day and night clothes
- Cell phone & charger
- Laptop or tablet and charger
- Medications
- List of medications that you take, and how often you take them
- Snacks/food for caregiver
- Something for caregiver to do while waiting (book, laptop)
- Phone list of contacts in treatment team
- Music, crossword puzzles, cards, board games, and other things for you to do at the hospital (as allowed by treatment center)
- Any personal items to make you more comfortable (photos, cards, favorite pillow, favorite blanket, preferred toiletries, slippers and so forth)
- Wallet card for CAR T
- Insurance cards

Remember, after you leave the hospital, you will need to:

- Stay near the hospital for at least 4 weeks. This means you are less than 30 minutes away by car. Some hospitals may permit you to be less than 60 minutes away by car. Your treatment team should tell you how close they would like you to be and for how long.
- Have a caregiver who is with you for 24/7 during that time.
- Know that you cannot drive or operate any heavy machinery for 8 weeks after the CAR T cell infusion.
- Know that you cannot donate blood, organs, tissues, and cells for transplant.

There are also steps your caregiver(s) can take to help prepare your home after your doctor says you can return. Some of the home preparation tasks include:

- Thoroughly clean home (shampoo carpets, wash floors, clean dust off furniture, clean bathrooms)
- Prepare clean bedding
- Remove plants
- Replace air conditioning and furnace filters

NEXT STEP PLANNING

Your next step will be **weeks 9–52 after infusion**. You can read more about what happens during these weeks in Chapter 15. There are 2 things you MUST do by 8 weeks after infusion or whenever you get released home.

☐ Turn to the next chapter and complete what you can in the tan checklist, “My Path.”

☐ Next, go to page 114 and complete the blue checklist, “Questions You Need Answered Before Weeks 9–52 After Infusion.”

15

Weeks 9–52 After Infusion

My Path

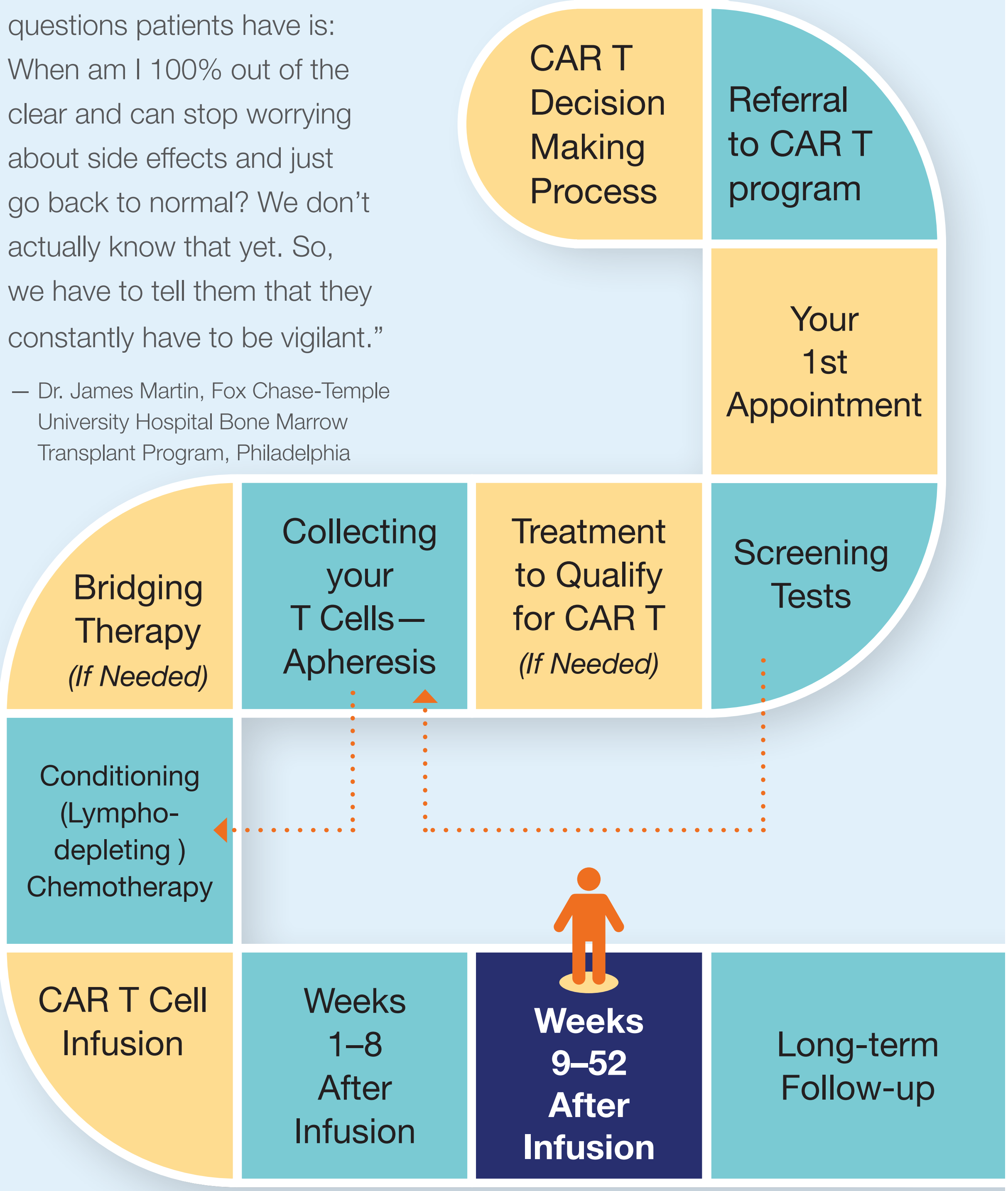
You will need to have follow-up appointments to see how CAR T has affected your tumor.

- ☐ I need to call to get a follow-up appointment. Contact information for CAR T center *(number)* ______________________________.
- ☐ My first follow-up appointment after I return home, is set for *(date & time)* _____ ______________________ at *(name of CAR T center or home medical clinic)* ______________________________.

  The address for my appointment is ______________________________ ______________________________.
- ☐ I will need follow-up appointments for the next ______________ years.
- ☐ Other ______________________________

CAR T Patient Journey Map

> “One of the most common questions patients have is: When am I 100% out of the clear and can stop worrying about side effects and just go back to normal? We don’t actually know that yet. So, we have to tell them that they constantly have to be vigilant.”
>
> — Dr. James Martin, Fox Chase-Temple University Hospital Bone Marrow Transplant Program, Philadelphia



The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor’s recommendation.

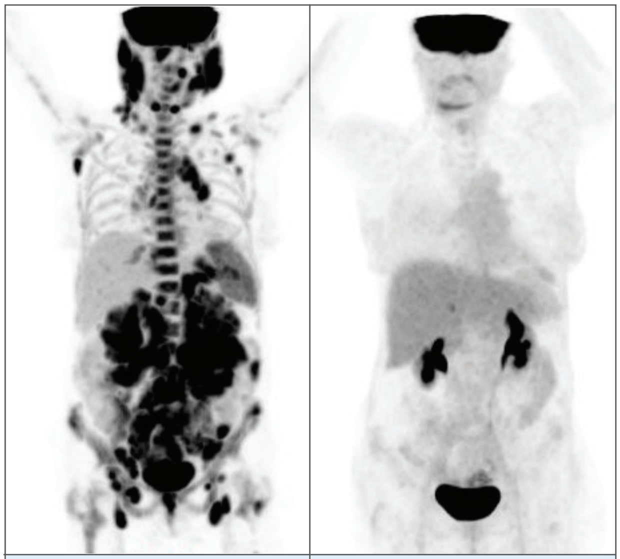
WEEKS 9–52

The CAR T team will want to follow-up with you after you return home. For some this may happen as early as 4 weeks, if they live close to the CAR T center. However, if you live further away from the center, you can typically return to your home after two months and be able to drive. After you return home, your CAR T team will work with your primary oncologist to see if you develop any late side effects.

If the therapy worked, you will likely have appointments every month for the 1st year after infusion. For some, this may be appointments at the CAR T center. For others, this may be checkups with your primary oncologist and bloodwork to be sent to your CAR T center. Your specific follow-up process will be determined by your CAR T doctor.

The 1st Follow-Up Appointment

You may be excited, nervous or anxious about your 1st follow up appointment. The main goal of this appointment is for your CAR T team to see how you are feeling. They will talk to you about what to expect next and what to continue to watch out for.



1 week before CAR T	1 month after CAR T

> "My pet scan images - 1 week prior to CAR T and then 1 month after. The initial scan shows how wide spread my lymphoma was, pretty much everywhere including in my bone marrow. The dark spots in the 1 month after image is normal organ function. These images illustrate the profound effectiveness of CAR T... I was in complete remission just 1 month out from CAR T."
>
> — Laurie, CAR T survivor

QUESTIONS YOU NEED ANSWERED BEFORE

Weeks 9–52 After Infusion

QUESTIONS TO ASK	NOTES
☐ Who should we contact if we have any questions?	
☐ Do I need IVIG infusions going forward? For how long? Where will I get the IVIG infusions?	
☐ Do I need to take any antibiotics or antiviral medications? If yes, what do you recommend?	
☐ What follow up tests should I have done in the future and when?	
☐ What side effects should we continue to look out for and for how long?	
☐ Who should be our first contact person if we detect a side effect? Who should we contact after hours? What's the contact information?	
☐ How can we manage these side effects at home?	
☐ Are there any other treatments or therapies that I need to have in the future?	
☐ Will I ever need to return to the CAR T treatment center for follow-up appointments? How often will my blood be checked for CAR T cells? Am I able to do the blood testing with my primary oncologist?	

☐ If my cancer is not in remission after CAR T cell therapy, what are some next steps I can take?	
☐ When can I expect to return to work/normal life?	
☐ What precautions do I need to take after treatment to make sure I am taking care of myself?	
☐ When can I start driving again?	
☐ Will long term follow up occur at the CAR T center? If yes, for how long? What does it entail?	
☐ Is a blood or marrow transplant recommended after CAR T?	
☐ Do I need to avoid certain foods, medications, or alcohol? If so, for how long?	

Other questions:

Returning to Work and Daily Life

Returning to work and daily activities may be physically and emotionally challenging. Take the time needed to process your journey and seek counseling or support. Get your doctor's approval before you return to work or your regular daily activities. Many patients return to work and regular activities anywhere from 1–6 months after they return home. When you do return to work, start part-time for 1-2 weeks to allow yourself time to rebuild your strength.

Remission

It can take anywhere from 30 days to 6 months to learn if your CAR T treatment has put you into remission. During that time, your primary oncologist will do tests and scans to see if your cancer is in remission or has recurred. If CAR T did not work, you can talk to your treatment team about other treatment options.

If CAR T did put you into remission, your primary oncologist and your CAR T team will work together to see if you need to take antibiotics or IVIG therapy to prevent infection. Your CAR T cells target all B-cells, not just the cancerous ones. This can cause low B cell counts (B cell aplasia) and increases your risk of infection. IVIG can help stop and prevent infections. Your primary oncologist can refill this prescription for IVIG infusions. You should also continue to prevent infections by practicing good hygiene and following the tips listed in the previous chapter.

For as long as you stay in remission, you will likely have appointments every year until 15 years after infusion. If you got CAR T cell therapy in a clinical trial, you may need to have your blood drawn every year and may have a follow-up appointment after 15 years. Know that you are not likely to have side effects for 15 years, but the FDA requires that you get check-ups for that long. If you had a blood or marrow transplant following CAR T cell therapy, your follow-up appointments and/or blood work testing may differ.

Long-Term Side Effects

Because CAR T cell therapy is so new, doctors are still learning about common long-term side effects. This is what CAR T patients say they have experienced:

- Runny nose with cough
- Vague pain where tumors used to be (phantom pains)
- More infections or getting sick more often (see next section about avoiding infections)
- Stomach problems (nausea, vomiting, diarrhea)
- Difficulty concentrating
- Forgetfulness
- Loss of appetite
- Weight loss
- Neuropathy (numbness in hands and feet)
- Fatigue and tiredness
- Joint pain
- Blood clots
- Dry Skin
- Hot flashes
- Constipation
- Skin rash
- Teeth sensitivity
- Severe leg and muscle cramping
- Depression and anxiety

Post-Treatment Survivorship

As you move beyond cancer and into remission and post-treatment survivorship, you will have unique needs as a cancer survivor. One of the most important things to remember is to maintain a healthy lifestyle. This means healthy eating, exercise, and maintaining your emotional health.

HEALTHY EATING

A healthy diet is critical to maintaining your health in general and is especially important for cancer survivors. Studies have shown that gaining weight after completing cancer treatments may increase your risk of a cancer recurrence. Additionally, proper nutrition and a balanced diet that is rich in calories, protein, vitamins, and minerals gives your body energy and nutrients to recover from treatment. To learn more about healthy eating for cancer survivors, tips, and recipes, read our *Frankly Speaking About Cancer: Eating Well for Cancer Survivors* booklet which is available at **www.CancerSupportCommunity.org/Beyond-Treatment**.

EXERCISE

Exercise is another important component to a maintaining a healthy lifestyle after remission. There are so many benefits to exercise:

- Keep or improve your physical abilities
- Improve balance and lower risk of falls or broken bones
- Improve blood flow and lower risk of blood clots
- Improve self-esteem
- Improve sexual functioning
- Lower risk of anxiety and depression
- Reduce impact from side effects such as nausea and fatigue
- Lower risk of heart disease and osteoporosis
- Aid with sleep
- Help prevent or improve cognitive symptoms
- Help maintain a healthy weight

Exercise can look different for each person. It can include walking, yoga, swimming, gardening, or movement in general. Its important that you find the exercise that is right for you and fits your body and schedule.

MAINTAINING YOUR EMOTIONAL HEALTH

Life after cancer treatment isn't always easy. You may experience a rollercoaster of emotions after treatment ends, including fear of recurrence. You may be sad or angry about the way cancer has affected your life. If you need to, talk to a counselor or psychologist or join a support group. Within the cancer community, there are others who will understand your experience and what you are feeling.

GET BACK TO WELLNESS: TAKE CONTROL OF YOUR SURVIVORSHIP

CANCER TRANSITIONS
MOVING BEYOND TREATMENT

The Cancer Transitions program was created by the Cancer Support Community to support, educate and empower people during the transition period following treatment—especially as people live longer and stronger lives after being treated for cancer. This program targets many of the physical, psychosocial, and practical issues that you and your loved ones may face now that cancer treatment is over. The primary issues covered in this program are nutrition, exercise, emotional health, and medical management.

Participants meet for a 2 hour session each week for 4 consecutive weeks. Expert presentations, group discussion, and an emphasis on setting and achieving active goals, will ensure that participants receive a unique and enriching experience.

To learn more about Cancer Transitions and how to join, visit www.CancerSupportCommunity.org/Cancer-Transitions.

3 months after her treatment, CAR T survivor Robyn, along with her husband and caregiver, Scott, got their scuba diving certification. Pictured from left to right is Scott, their son John, and Robyn during a dive off Bora Bora in French Polynesia.

QUESTIONS TO ASK AT

Weeks 9–52 After Infusion

QUESTIONS TO ASK	NOTES
☐ How often do I need follow-up appointments and scans?	
☐ Will I need to return to the CAR T center for follow-up appointments, or can I have them locally with my primary oncologist?	
☐ How do I schedule follow-up appointments? Is there a scheduler I should work with? What is the contact information?	
☐ What should I bring with me to these appointments?	
☐ What are my limitations after I am able to return home? Do I still need to have my caregiver with me 24/7? Can I have visitors and receive flowers?	
☐ Who should be our first contact person if we detect a side effect? Who should we contact after hours?	
☐ What possible short- and long-term side effects should we look out for?	
☐ How can we manage these side effects at home?	
☐ Are there any other treatments or therapies that I need to have in the future?	
☐ If my cancer is not in remission after CAR T cell therapy, what are some next steps I can take?	

☐ When can I expect to return to work/normal life?	
☐ When will it be safe for me to resume sexual activity?	
☐ When can I drive again?	
☐ When will it be safe for me to resume moderate exercise?	
☐ What precautions do I need to take after treatment to make sure I am taking care of myself?	
☐ Do you have a reimbursement policy? If yes, how can I get reimbursed for the expenses of this treatment?	
☐ What support groups or programs can I join to help me transition out of treatment?	

Other questions:

You may find that you continue to need support after treatment. Try speaking to a social worker, joining a support group, or joining a Facebook group for your cancer type or for CAR T cell therapy.

As mentioned, if you are in remission after the first year following CAR T, you will continue to have long-term follow-up appointments for about 15 years. Talk to your doctor and CAR T treatment team to better understand where that will happen, what that will entail, and how often.

Section 3

Resources and Record Keeping

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S CLUB

My Treatment Team Contacts

Write contact information on the next few pages for all the different people on your treatment team or staple their business cards onto the pages. Here are just some of the types of treatment team members you should collect contact information from and know when you should contact them:

- My primary oncologist
- My primary CAR T cell therapy physician (oncologist, hematologist, expert in stem cell transplants, or principal investigator)
- CAR T Team Coordinators, Schedulers, and Nurse Navigators
- Nurses, Advanced Practice Nurses, and Physician Assistants who coordinate your CAR T care
- Clinical trial navigators
- Apheresis clinic staff
- Social workers who can help you coordinate your care, find resources and financial support, and manage logistics and cost of care (may be available through your insurance or at your CAR T center)
- Financial counselor (may be available through your insurance or at your CAR T center)
- Physicians, nurses, and residents who will provide inpatient care while you are in the hospital
- Neurologists, endocrinologists, infectious disease specialists palliative care providers and others who may monitor and treat your side effects
- An intensive care team, if you are admitted to the intensive care unit (ICU)

MY TREATMENT TEAM CONTACTS

Name & Role ____
Facility & Location ____
I should contact this person if ____________________________________
Phone number ____
Email ____

Name & Role ____
Facility & Location ____
I should contact this person if ____________________________________
Phone number ____
Email ____

Name & Role ____
Facility & Location ____
I should contact this person if ____________________________________
Phone number ____
Email ____

Name & Role ____
Facility & Location ____
I should contact this person if ____________________________________
Phone number ____
Email ____

MY TREATMENT TEAM CONTACTS

Name & Role ____

Facility & Location ______________________________________

I should contact this person if ___________________________

Phone number ____

Email ____

Name & Role ____

Facility & Location ______________________________________

I should contact this person if ___________________________

Phone number ____

Email ____

Name & Role ____

Facility & Location ______________________________________

I should contact this person if ___________________________

Phone number ____

Email ____

Name & Role ____

Facility & Location ______________________________________

I should contact this person if ___________________________

Phone number ____

Email ____

Resources for Lodging

Ask your CAR T team and your insurer if they offer support with lodging. In addition, there are resources from several nonprofit organizations that help cancer patients and caregivers with some of their housing needs during treatment:

American Cancer Society Patient Lodging

800-227-2345 • **www.bit.ly/ACSLodging**
Provides lodging at Hope Lodges and hotels across the United States

Hotel Keys of Hope

800-227-2345 • **www.bit.ly/KeyOfHope**
Extended Stay America has partnered with the American Cancer Society to provide free and discounted hotel room stays to cancer patients receiving treatment away from home

Joe's House

877-563-7468 • **www.joeshouse.org/**
Online search tool that helps cancer patients and their families find a place to stay when traveling for medical treatment

Resources for Transportation

Ask your CAR T team and your insurer if they offer transportation support. There are many nonprofit organizations who support cancer patients and caregivers with finding, securing, and paying for transportation costs, including air and ground transportation.

Air Charity Network
877-621-7177 • **www.aircharitynetwork.org**
Free flights for people who cannot fly commercially because of financial or medical need

Mercy Medical Angels
www.mercymedical.org
Airplane flights, gas cards, and bus and train tickets for patients with financial need

Corporate Angel Network
914-328-1313 • **www.corpangelnetwork.org**
Free flights for cancer patients on corporate aircrafts

Good Days Travel Assistance Program
877-968-7233 • **www.mygooddays.org**
Arranges and pays for travel costs for patients with financial need

Leukemia & Lymphoma Society's Travel Assistance Programs
877-557-2672 • **www.lls.org/support/financial-support**
Financial assistance with travel expenses for blood cancer patients with financial need

American Cancer Society Road to Recovery Program
800-227-2345 • **www.bit.ly/ACSTransport**
Offers free rides to and from treatment for people with cancer who do not have a ride or are unable to drive themselves

Patient Advocate Foundation
800-532-5274 • **www.patientadvocate.org**
Their National Financial Resource Directory can help you find national and regional resources for transportation, lodging, and financial assistance

Patient AirLift Services (PALS)
631-694-7257 • **www.palservices.org/**
Free flights for patients with financial need

Resources for Patients & Caregivers

ONLINE AND TELEPHONE SOURCES OF SUPPORT

CAR T Cancer Support Helpline

844-792-6517 • **www.CancerSupportCommunity.org/Helpline**

Whether you are newly diagnosed with cancer, a longtime cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free CAR T Cancer Support Helpline is available in 200 languages. The Cancer Support Helpline Community Navigators are licensed social workers and specially trained to provide help to patients, caregivers and family members to address social, emotional, practical and financial barriers to care. The Community Navigators provide timely access to quality individualized assistance from before cancer diagnosis through all phases of the cancer experience. We are available to assist you Mon-Fri 9am - 9pm ET and Sat-Sun 9am – 5pm ET.

MyLifeLine

www.MyLifeLine.org

CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. MyLifeLine's discussion boards are moderated by a licensed professional and are available 24 hours/day, 7 days/week.

Leukemia & Lymphoma Society's First Connection Programs

www.lls.org/support/peer-to-peer-support

A free service of The Leukemia & Lymphoma Society (LLS) that introduces patients and their loved ones to a trained peer volunteer who has gone through a similar experience.

CAR T-CELL Patients And Carers Facebook Group

www.bit.ly/FBCART

This private Facebook group and is the largest online group of CAR T patients and caregivers. It serves as a space to discuss patient and family stores of CAR T cell therapies, find support, and share information.

Imerman Angels

www.imermanangels.org/

Provides free personalized one-on-one cancer support for cancer fighters, survivors and caregivers. Through their unique matching process, they partner individuals seeking support through the cancer journey with a "Mentor Angel."

Cancer Research Institute ImmunoCommunity

www.cancerresearch.org/patients/immunocommunity
Read real stories of inspiration and lessons learned, or connect directly with ImmunoAdvocates about their experience with immunotherapy treatment, including CAR T.

SUPPORT FOR MAKING TREATMENT DECISION

You can get help thinking through questions to ask your CAR T team to be sure that CAR T therapy is the right choice for you from CSC's *Open to Options* program. Our trained specialists can help you create a list of questions to share with your CAR T team. Make an appointment by calling CSC's Helpline at 844-792-6517 or visiting a local CSC or Gilda's Club. Find the location nearest to you: **www.CancerSupportCommunity.org/FindLocation**.

IN-PERSON SUPPORT

You and your caregiver may want to see if there is a local Cancer Support Community (CSC), Gilda's Club, or another cancer support group/wellness center near where you live and/or where you will be getting CAR T cell therapy. Taking advantage of support groups, wellness classes, and other ways of gathering a community of support will be very helpful to reduce stress and anxiety while you are waiting and then once you are going through the process. There is much strength in community.

Call 844-792-6517 or visit **www.CancerSupportCommunity.org/FindLocation**.

The Leukemia & Lymphoma Society may also have in-person support groups near where you live and/or where you will be getting CAR T cell therapy.

Call 800-955-4572 or visit **www.lls.org/support-groups**.

RESOURCES FOR CAREGIVERS

Ask your health care team and the CAR T team for other resources for the social, emotional, physical, and practical support you and your caregiver need now and will need during the CAR T process.

Cancer Support Community

- Education, resources, and tools from the *Frankly Speaking About Cancer: Caregivers* program: **www.CancerSupportCommunity.org/caregivers**
- Online CAR T Discussion Board on MyLifeLine Community: **www.MyLifeLine.org**
- Cancer Support Helpline: 844-792-6517

Blood & Marrow Transplant (BMT) Infonet

- Caring Connections Program: **www.bmtinfonet.org/get-help** • 888-597-7674
- Resources on Role of the Family Caregiver: **www.bmtinfonet.org/transplant-article/role-family-caregiver**

CancerCare

- Caregiving Resources: **www.cancercare.org/caregiving**

Caregiver Action Network

- Resources, education, and support: **www.caregiveraction.org**
- Caregiver Help Desk: 855-227-3640

Help for Cancer Caregivers

- Make a Personal Caregiver Guide: **www.helpforcancercaregivers.org**

Leukemia and Lymphoma Society

- Education, resources and tools: **www.lls.org/caregiver-support** • 800-955-4572
- LLS Community: **www. communityview.lls.org**

Lymphoma Research Foundation

- Resources for patients and caregivers: **www.lymphoma.org**
- LRF Helpline: 800-500-9976

FINANCIAL & EMPLOYMENT RESOURCES

Triage Cancer

https://triagecancer.org/ • 424-258-4628
Free education on the practical and legal issues that arise after a cancer diagnosis

Cancer and Careers

www.cancerandcareers.org/en
Empowers and educates people with cancer to thrive in their workplace

Patient Advocate Foundation

800-532-5274 • www.patientadvocate.org
Their National Financial Resource Directory can help you find national and regional resources for transportation, lodging, and financial assistance

Resources for Clinical Trials

The National Institutes of Health (NIH) is a federal agency that has a large database of clinical trials. Go to **www.clinicaltrials.gov** to find studies across the United States and internationally.

There are many organizations that can you help learn more about clinical trials or can connect you with a patient navigator to help you search for a CAR T clinical trial.

Some organizations offer free clinical trial navigators who can assist you when searching for a CAR T clinical trial.

Cancer Support Community

- Education, resources, and tools from the *Frankly Speaking About Cancer: Clinical Trials* program: **www.CancerSupportCommunity.org/ClinicalTrials**
- Cancer Support Helpline: 844-792-6517

National Cancer Institute (NCI)

- Online search tool for clinical trials: **www.cancer.gov/clinicaltrials**
  800-4-CANCER (800-422-6237)

American Cancer Society

- Clinical Trials Information: **www.cancer.org/clinicaltrials**
- Cancer Helpline: 800-227-2345

Leukemia & Lymphoma Society

- Clinical Trial Support Center: **www.lls.org/clinicaltrials** • 800-955-4572

Lymphoma Research Foundation

- Clinical Trials Information Service: **https://lymphoma.org/resources/supportservices/ctis/**
  800-500-9976

Center for Information and Study on Clinical Research Participation (CISCRP)

- Online tool to search for clinical trials: **www.ciscrp.org** • 877-MED HERO

CenterWatch

- Online tool to search for clinical trials: **www.centerwatch.com/clinical-trials/**
  617-856-5900

Cancer Research Institute

- Cancer Immunotherapy Clinical Trial Finder:
  www.cancerresearch.org/clinical-trials • 855-216-0127

Record Keeping

This next section contains tools to help you keep track of your appointments, treatments, and a place to note your thoughts and questions. Talk openly with your treatment team about what you are experiencing. They can work with you to help address your physical, emotional and practical concerns.

If you need more copies of any of the record keeping pages, you can always go to **www.CancerSupportCommunity.org/CARTGuide** to access the digital version of this guidebook and print copies of needed pages.

YOUR HEALTH CARE PLAN (Including Medicare/Medicaid)

Name ______________________________

Member ID______________ Group Number ______________

Address ______________________________

Phone______________ Fax ______________

Website ______________________________

Name ______________________________

Member ID______________ Group Number ______________

Address ______________________________

Phone______________ Fax ______________

Website ______________________________

Name ______________________________

Member ID______________ Group Number ______________

Address ______________________________

Phone______________ Fax ______________

Website ______________________________

YOUR HEALTH CARE PLAN (Including Medicare/Medicaid)

Name ____

Member ID ______________________ Group Number ______________________

Address ____

Phone ______________________ Fax ______________________

Website ____

Name ____

Member ID ______________________ Group Number ______________________

Address ____

Phone ______________________ Fax ______________________

Website ____

Name ____

Member ID ______________________ Group Number ______________________

Address ____

Phone ______________________ Fax ______________________

Website ____

YOUR PHARMACIES (At home & near the CAR T center)

Name ____

Address ____

Phone ____________________ Fax ____________________

Website ____

Name ____

Address ____

Phone ____________________ Fax ____________________

Website ____

Name ____

Address ____

Phone ____________________ Fax ____________________

Website ____

YOUR PHARMACIES (At home & near the CAR T center)

Name ______________________________

Address ______________________________

Phone ______________ Fax ______________

Website ______________________________

Name ______________________________

Address ______________________________

Phone ______________ Fax ______________

Website ______________________________

Name ______________________________

Address ______________________________

Phone ______________ Fax ______________

Website ______________________________

AGENCIES & ORGANIZATIONS

Include visiting nurse/home health agencies, support organizations and transportation services.

Name ____

Address ____

Phone ____________________ E-mail ____________________

Website ____

Notes ____

Name ____

Address ____

Phone ____________________ E-mail ____________________

Website ____

Notes ____

Name ____

Address ____

Phone ____________________ E-mail ____________________

Website ____

Notes ____

AGENCIES & ORGANIZATIONS

Name ______________________________

Address ______________________________

Phone ______________ E-mail ______________

Website ______________________________

Notes ______________________________

Name ______________________________

Address ______________________________

Phone ______________ E-mail ______________

Website ______________________________

Notes ______________________________

Name ______________________________

Address ______________________________

Phone ______________ E-mail ______________

Website ______________________________

Notes ______________________________

OTHER IMPORTANT CONTACTS

Include family and friends, neighbors, work associates, clergy, etc.

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

OTHER IMPORTANT CONTACTS

Name ____

Address ______________________________________

Phone __________________ E-mail __________________

Role ____

Name ____

Address ______________________________________

Phone __________________ E-mail __________________

Role ____

Name ____

Address ______________________________________

Phone __________________ E-mail __________________

Role ____

OTHER IMPORTANT CONTACTS

Include family and friends, neighbors, work associates, clergy, etc.

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

RESOURCES (For support, transportation, logistics, Caregivers, etc.)

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

Name ____

Address ____

Phone ____________________ E-mail ____________________

Role ____

RESOURCES (For support, transportation, logistics, Caregivers, etc.)

Name ______________________________

Address ______________________________

Phone ______________ E-mail ______________

Role ______________________________

Name ______________________________

Address ______________________________

Phone ______________ E-mail ______________

Role ______________________________

Name ______________________________

Address ______________________________

Phone ______________ E-mail ______________

Role ______________________________

CALENDAR

Month ____

MONDAY	TUESDAY	WEDNESDAY

CALENDAR

Month ____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month ____

MONDAY	TUESDAY	WEDNESDAY

CALENDAR

Month ____________________

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month ____

MONDAY	TUESDAY	WEDNESDAY

CALENDAR

Month ____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month ____

MONDAY	TUESDAY	WEDNESDAY

CALENDAR

Month ____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month ____

MONDAY	TUESDAY	WEDNESDAY

CALENDAR

Month ____________________

THURSDAY	FRIDAY	SATURDAY/SUNDAY

CALENDAR

Month ____

MONDAY	TUESDAY	WEDNESDAY

CALENDAR

Month ______________________________

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

APPOINTMENT NOTES

Date/time____

Appointment with____________________________________

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time____

Appointment with____

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time____

Appointment with____________________________________

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time____

Appointment with______________________________________

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time____

Appointment with____________________________________

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time____

Appointment with____

Questions to Ask

Notes

Follow-up / Action Steps

TREATMENT LOG

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

TREATMENT LOG

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

TREATMENT LOG

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

TREATMENT LOG

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

Treatment Name	
Start Date	Comments
Stop Date	
No. of Treatments/Cycles	

MEDICATION LOG

Drug Name Depakote

Prescribed for migraines

Start Date 1/5

Prescriber 1/26

Stop Date Dr. Smith

Side Effects Nausea

Dosage Schedule ☑ am ☐ noon ☑ pm ☐ bedtime ☐ as needed

Dosage and Special Instructions

Drug Name

Prescribed for

Start Date

Prescriber

Stop Date

Side Effects

Dosage Schedule ☐ am ☐ noon ☐ pm ☐ bedtime ☐ as needed

Dosage and Special Instructions

MEDICATION LOG

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule ☐ am ☐ noon ☐ pm ☐ bedtime ☐ as needed	
Dosage and Special Instructions	

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule ☐ am ☐ noon ☐ pm ☐ bedtime ☐ as needed	
Dosage and Special Instructions	

MEDICATION LOG

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects

Dosage Schedule ☐ am ☐ noon ☐ pm ☐ bedtime ☐ as needed

Dosage and Special Instructions

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects

Dosage Schedule ☐ am ☐ noon ☐ pm ☐ bedtime ☐ as needed

Dosage and Special Instructions

MEDICATION LOG

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects

Dosage Schedule ☐ am ☐ noon ☐ pm ☐ bedtime ☐ as needed

Dosage and Special Instructions

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects

Dosage Schedule ☐ am ☐ noon ☐ pm ☐ bedtime ☐ as needed

Dosage and Special Instructions

TEST LOG

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

TEST LOG

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
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TEST LOG

Name of Test	Date
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Name of Test	Date
Notes	

Name of Test	Date
Notes	

TEST LOG

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

SIDE EFFECTS TRACKER

This tracker can help you note and report side effects to discuss with your health care team. Ask your doctor about the side effects you should watch out for or report right away. Know the best number to call if you experience urgent side effects. Keep detailed notes describing how you felt, how severe the symptom was, any other symptoms that happened at the same time, what you were doing when the symptom began and what you did that helped or didn't help.

Side Effect Nausea	
Date/Time March 5, 10 pm	Notes Relieved by lying still for 10 minutes
Date/Time March 6, 9 am	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

SIDE EFFECTS TRACKER

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

SIDE EFFECTS TRACKER

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

SIDE EFFECTS TRACKER

Side Effect

Date/Time

Date/Time

Date/Time

Notes

Side Effect

Date/Time

Date/Time

Date/Time

Notes

Side Effect

Date/Time

Date/Time

Date/Time

Notes

SIDE EFFECTS TRACKER

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

SIDE EFFECTS TRACKER

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

Side Effect	
Date/Time	Notes
Date/Time	
Date/Time	

NOTES

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NOTES

Acknowledgments

We'd like to extend a special thank you to the patients and caregivers who participated in focus groups, interviews, surveys, photos, and videos. Their generosity in sharing their experiences shaped the development of this program.

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ABOUT THE CANCER SUPPORT COMMUNITY

www.CancerSupportCommunity.org

The Cancer Support Community (CSC) is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, health-care partnerships, and satellite locations that deliver more than $50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people each year. Formed in 2009 by the merger of The Wellness Community and Gilda's Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer. In January 2018, CSC welcomed Denver-based nonprofit MyLifeLine, a digital community that includes more than 40,000 patients, caregivers, and their supporters that will enable CSC to scale its digital services in an innovative, groundbreaking way.

CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S
CLUB

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This book is available to download and print yourself at **www.CancerSupportCommunity.org/CART**. For print copies or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.