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

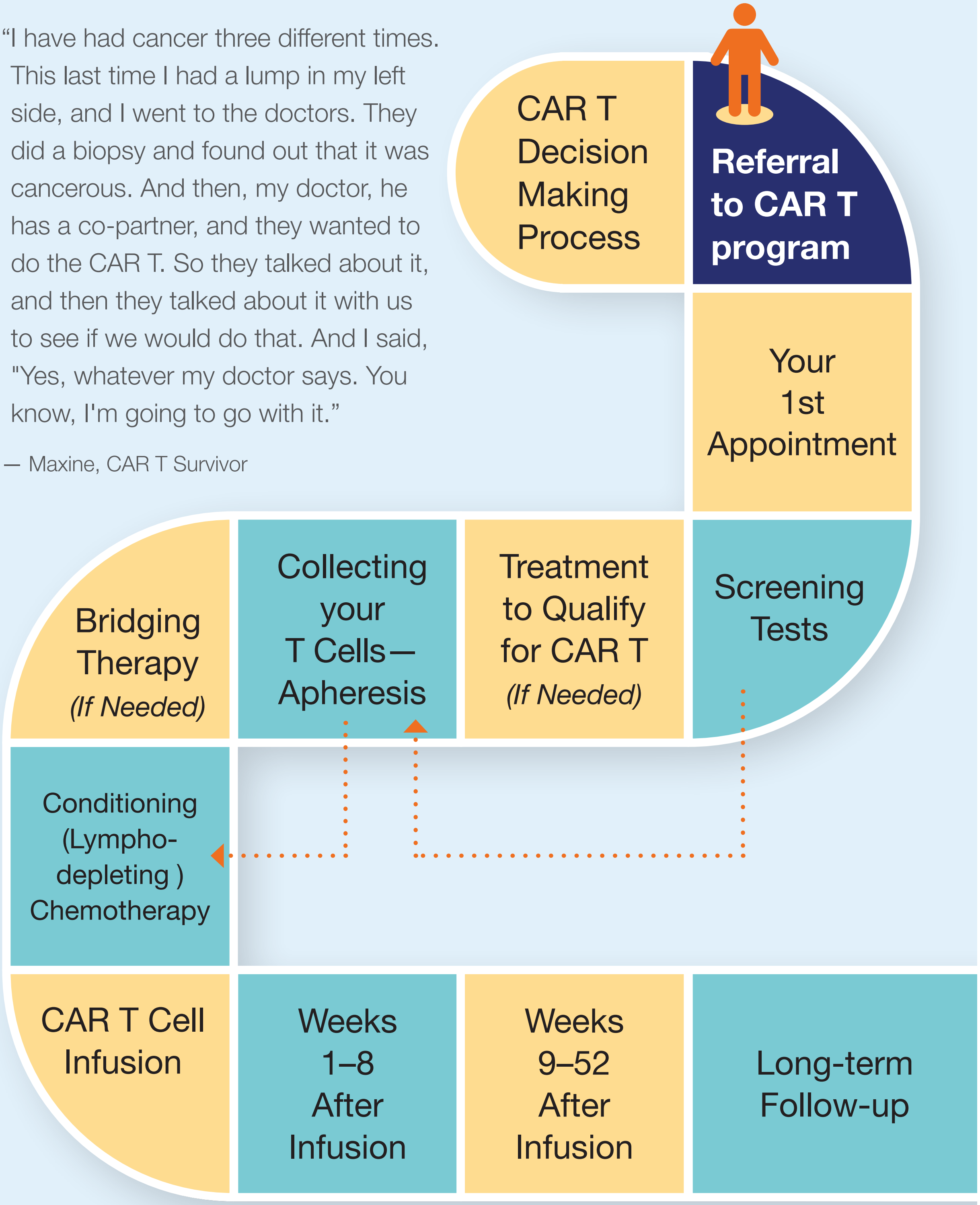
Referral to CAR T Program

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



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.

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.

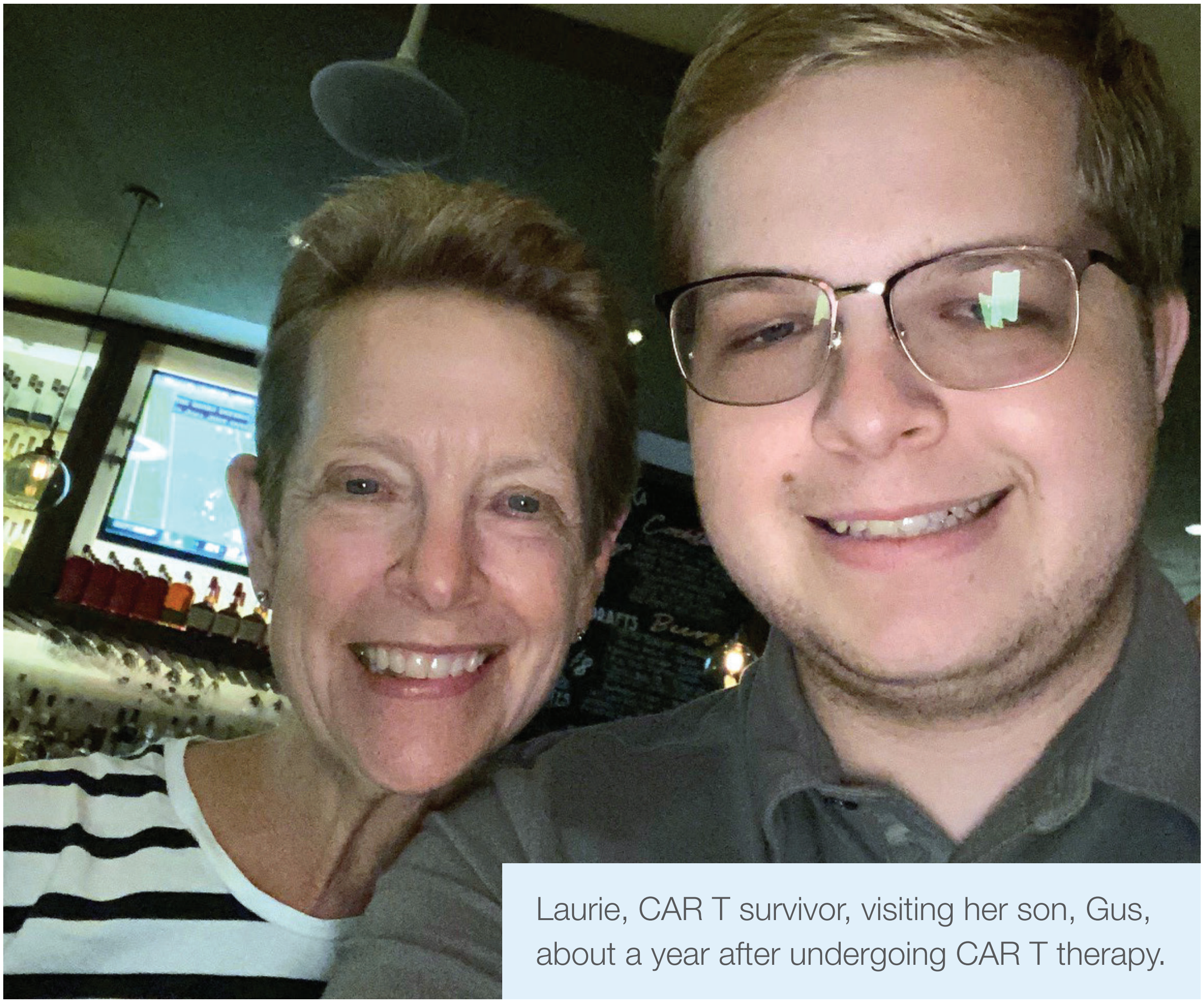
After the first visit with the CAR T team, most people go back home. They return later to start treatment once they are approved to move forward.

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)* ____________________ .

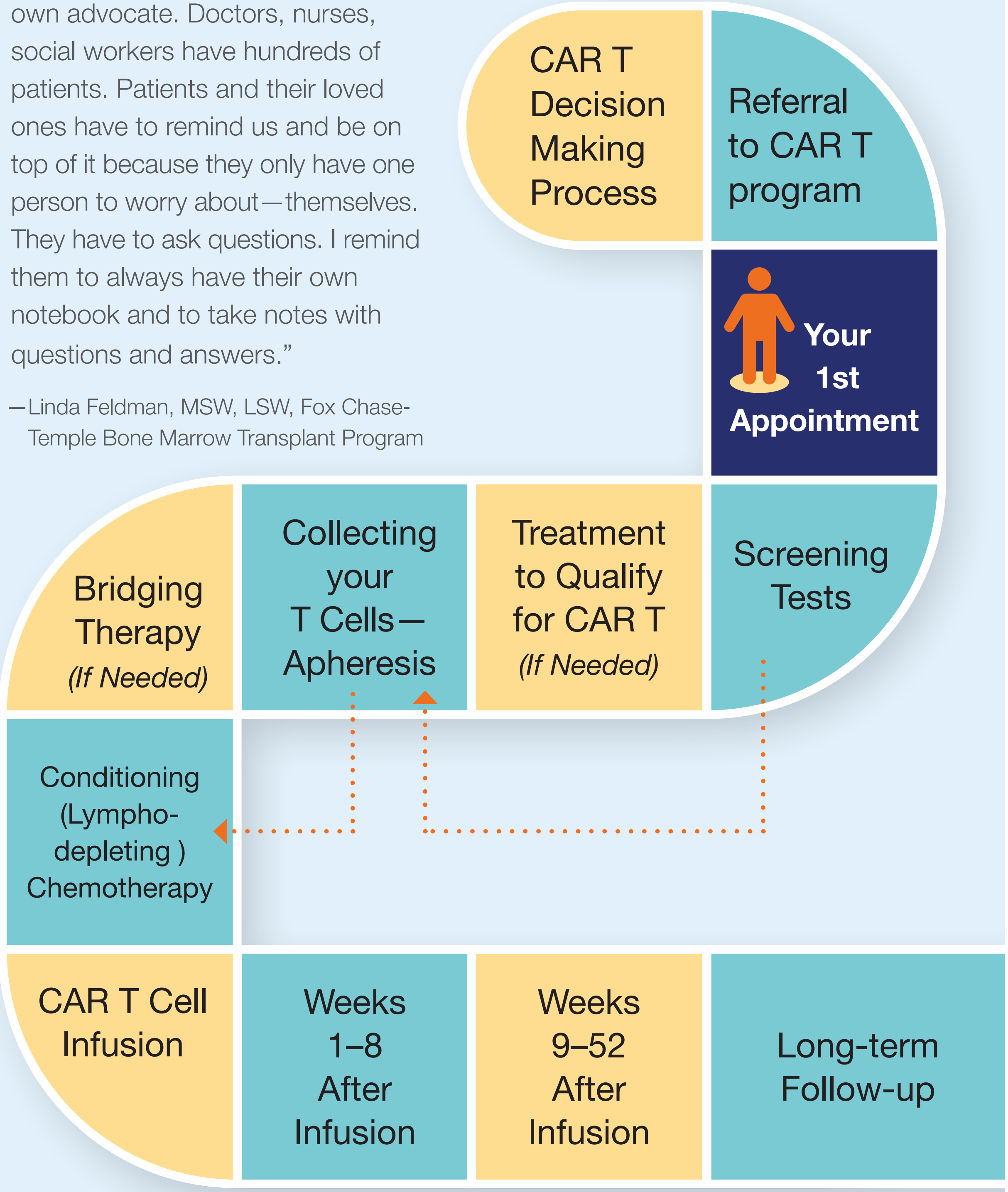
☐ The address for my appointment is ______________________________________
____ .

☐ 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

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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

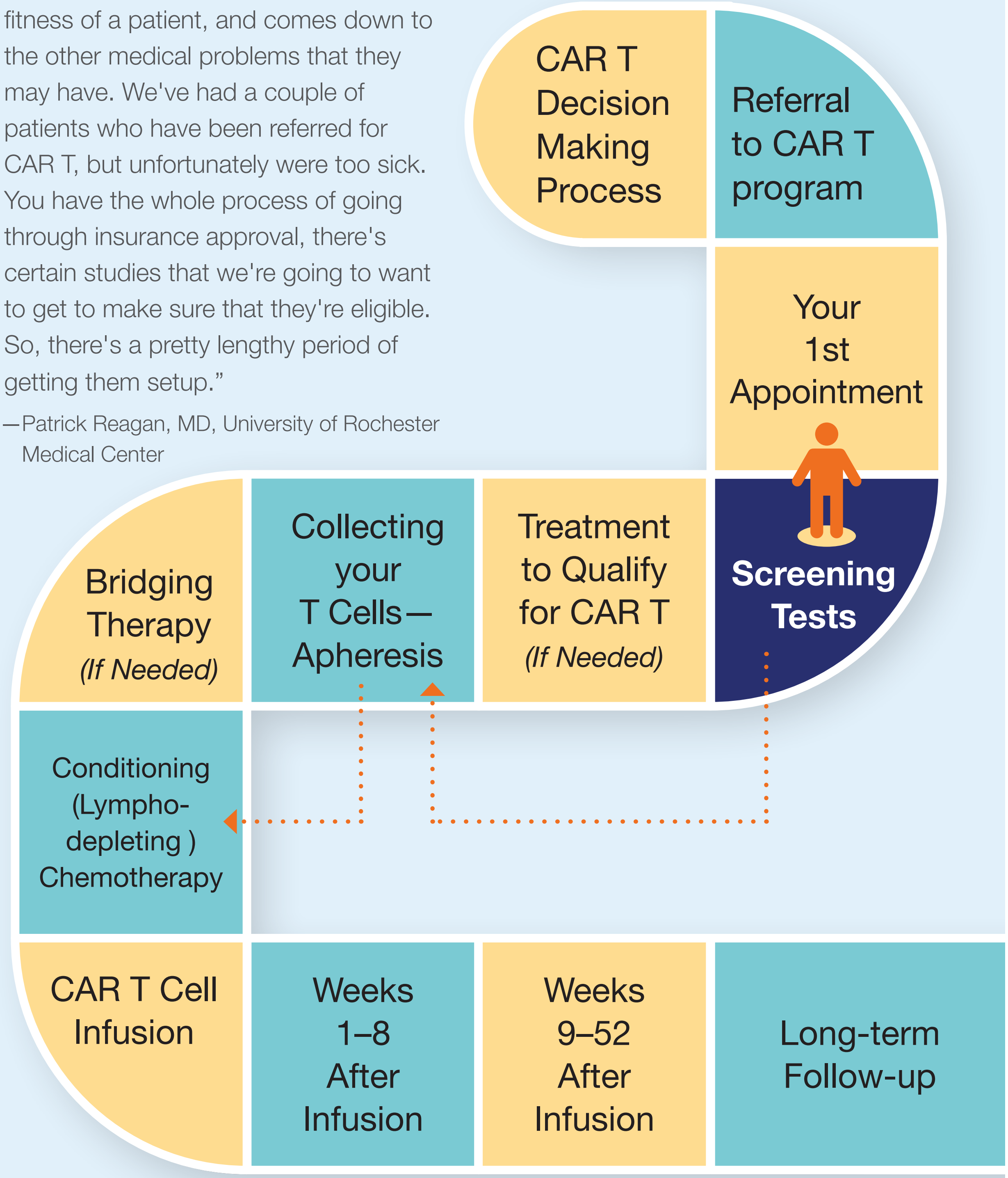
(date) ____________________, I should call *(name)* ____________________________

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



CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

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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.

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)* ____ .

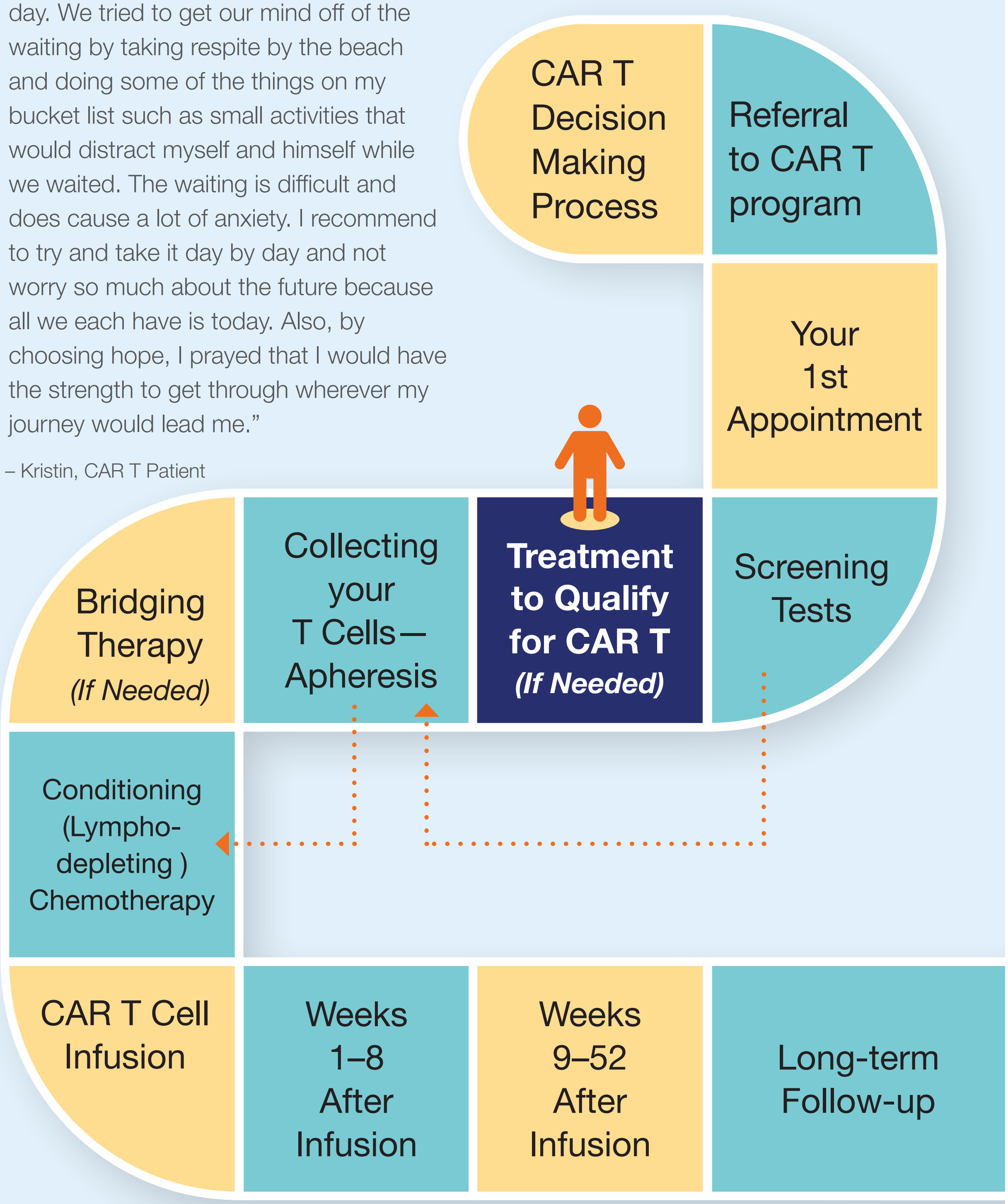
☐ My appointment is scheduled for *(date and time)* ______________________________

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



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 ____

____

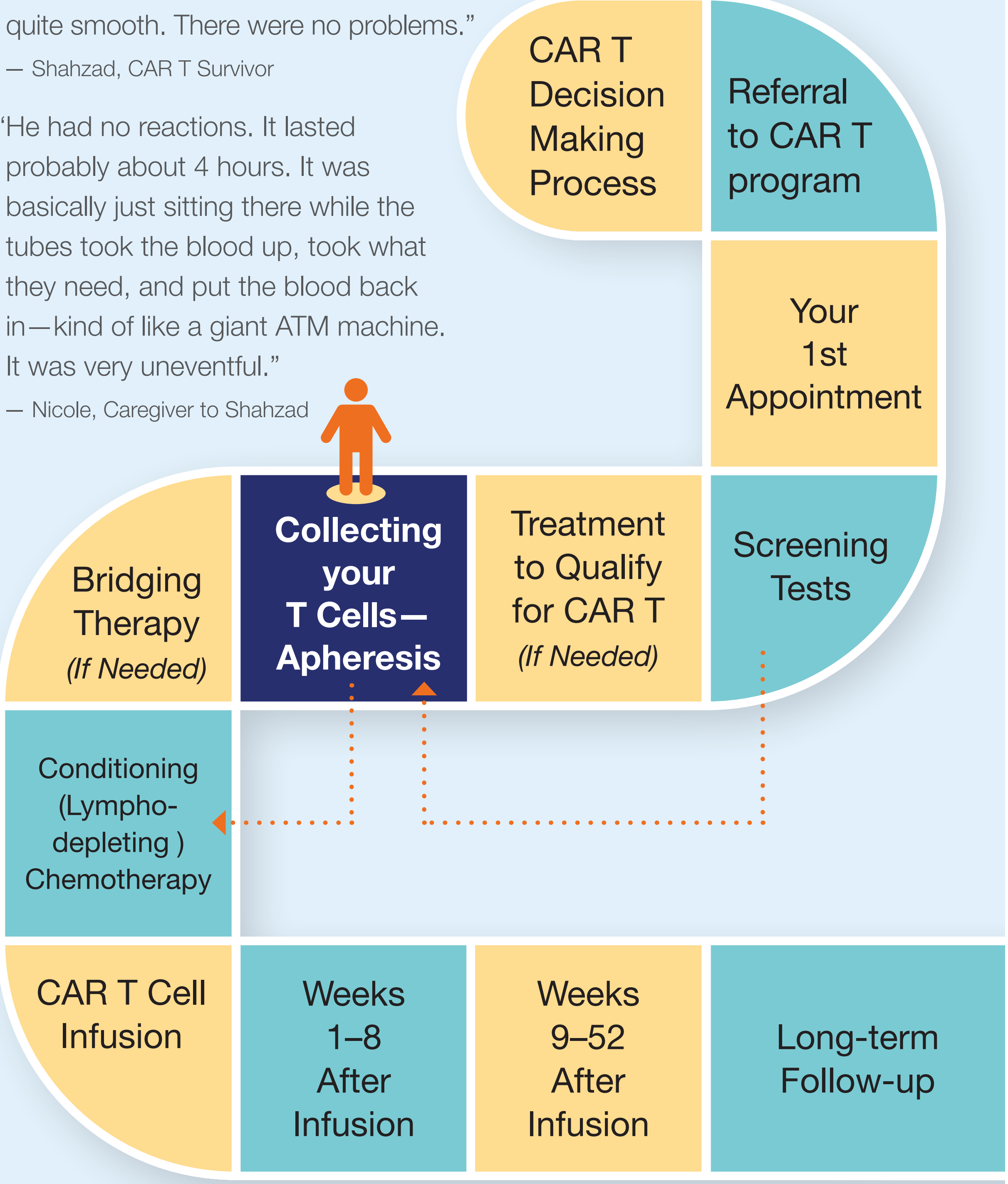
CAR T Patient Journey Map

“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

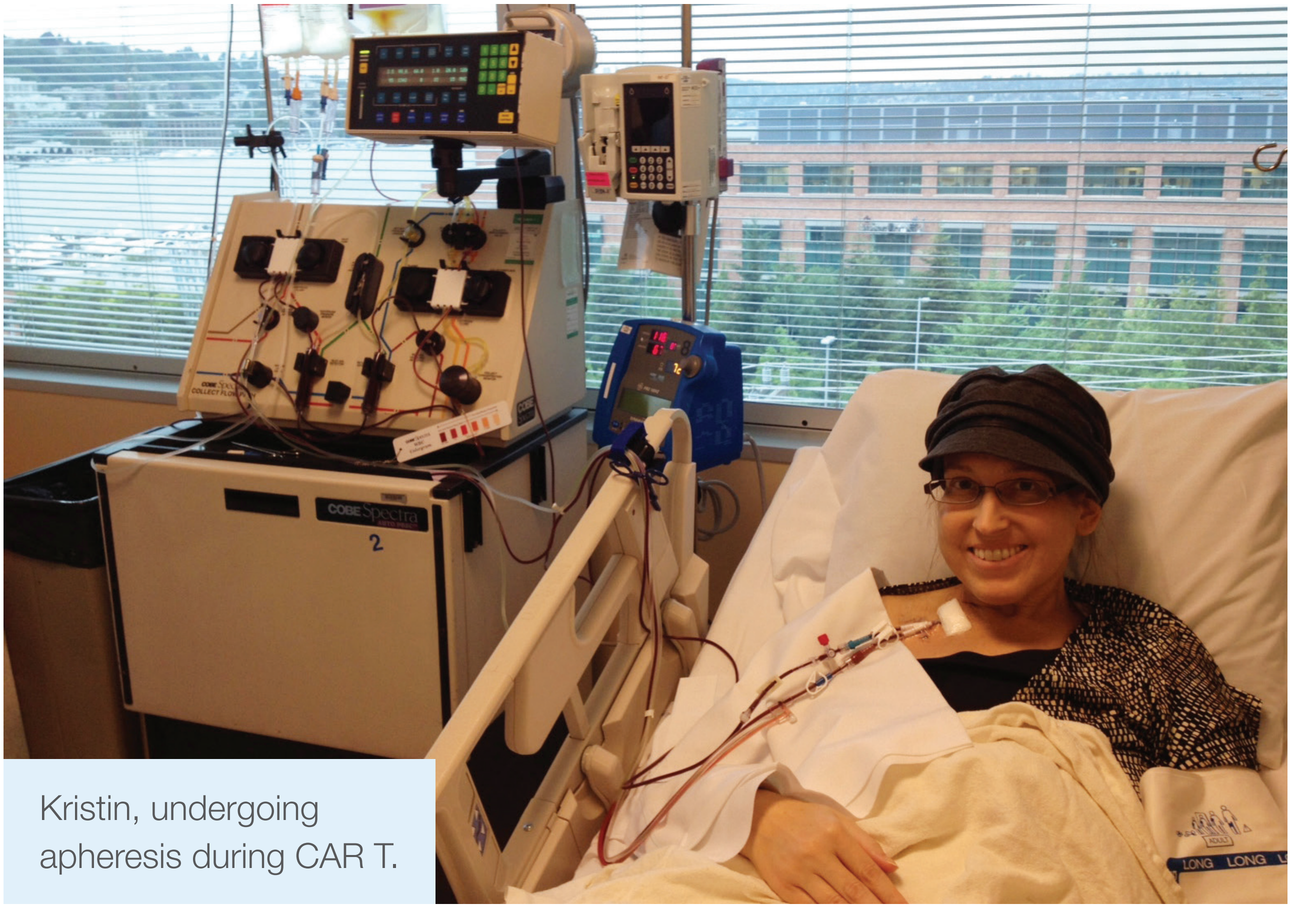
The orange dotted lines highlight that you may be able to skip some steps in the CAR T journey, based on your doctor’s recommendation.

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

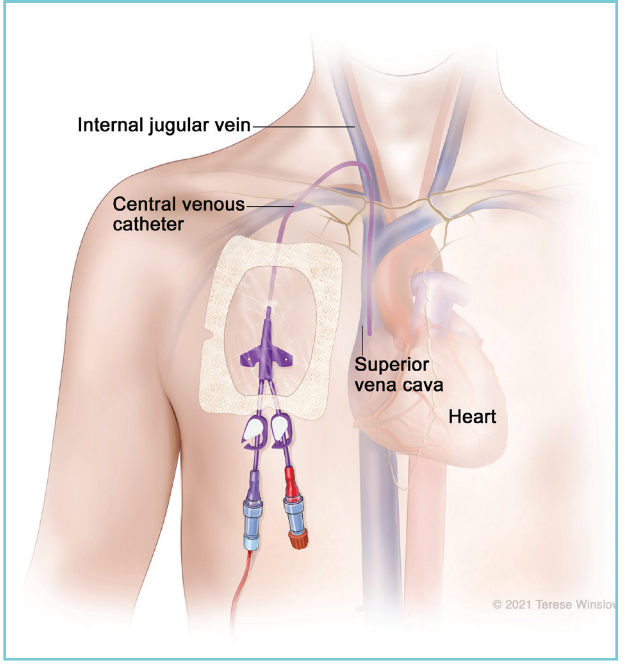
In order to get access to your T cells, the apheresis team will need to insert either a special type of catheter or 2 IV's in your arms. Even if you already have a port in place, you may need to have a different one inserted for this process. If the veins in your arms can accommodate a large needle, 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



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)* _______________________________ .

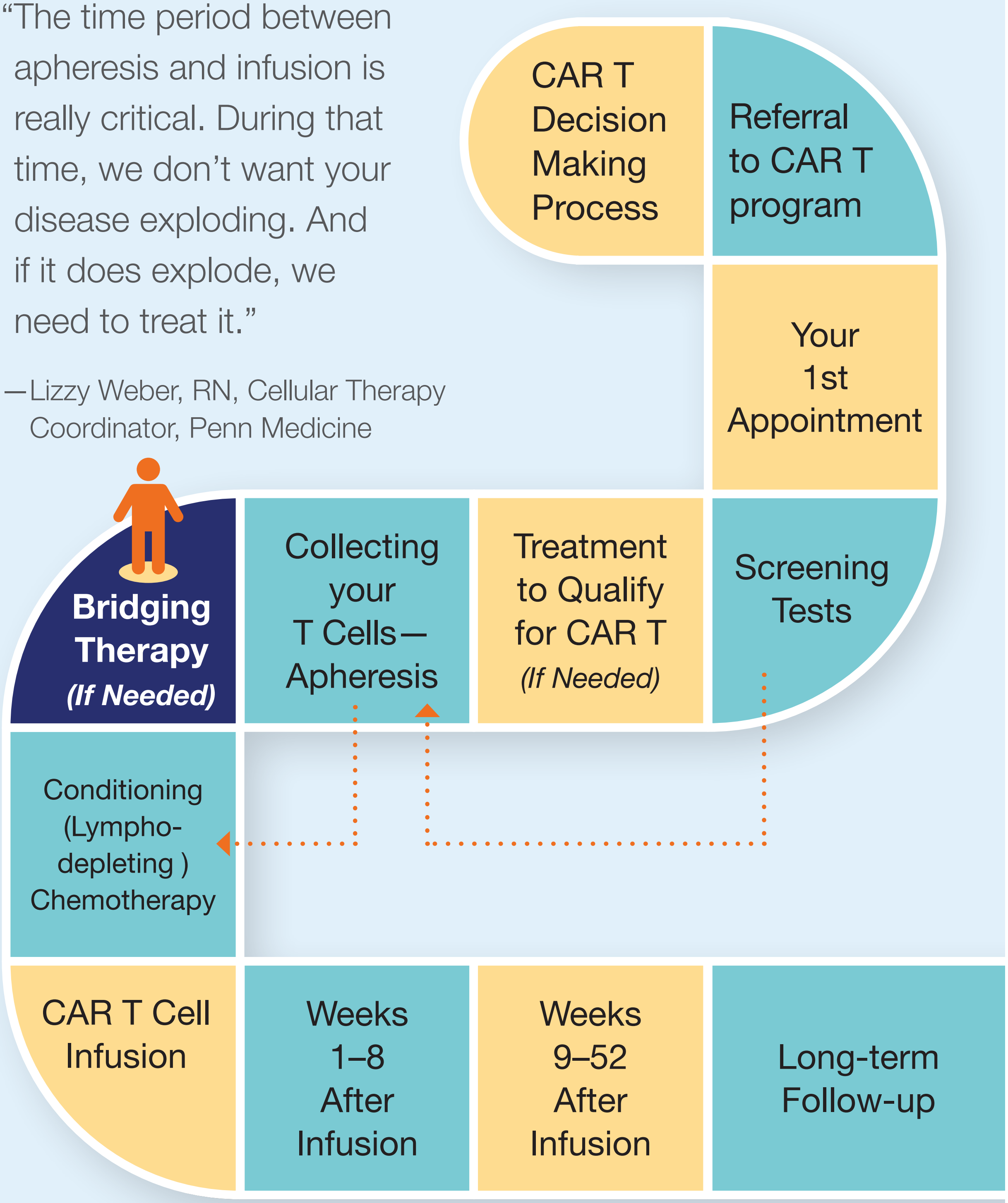
I should show up for my appointment at *(address)*__________________________ .

☐ 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)* ____________________ .

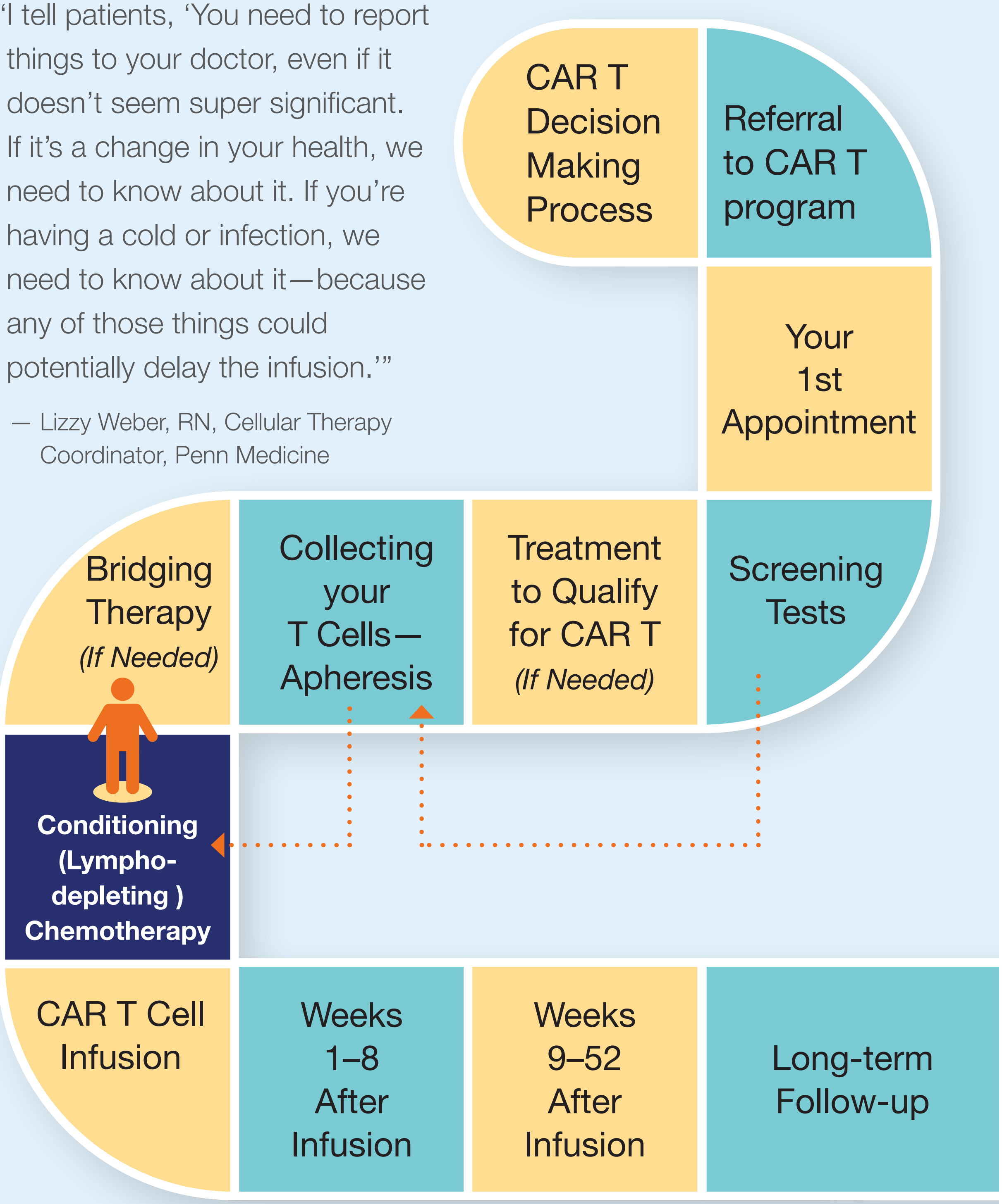
☐ I will start conditioning chemotherapy appointment on *(date & time)* __________

____ .

☐ 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

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 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)* _______________________
____ .

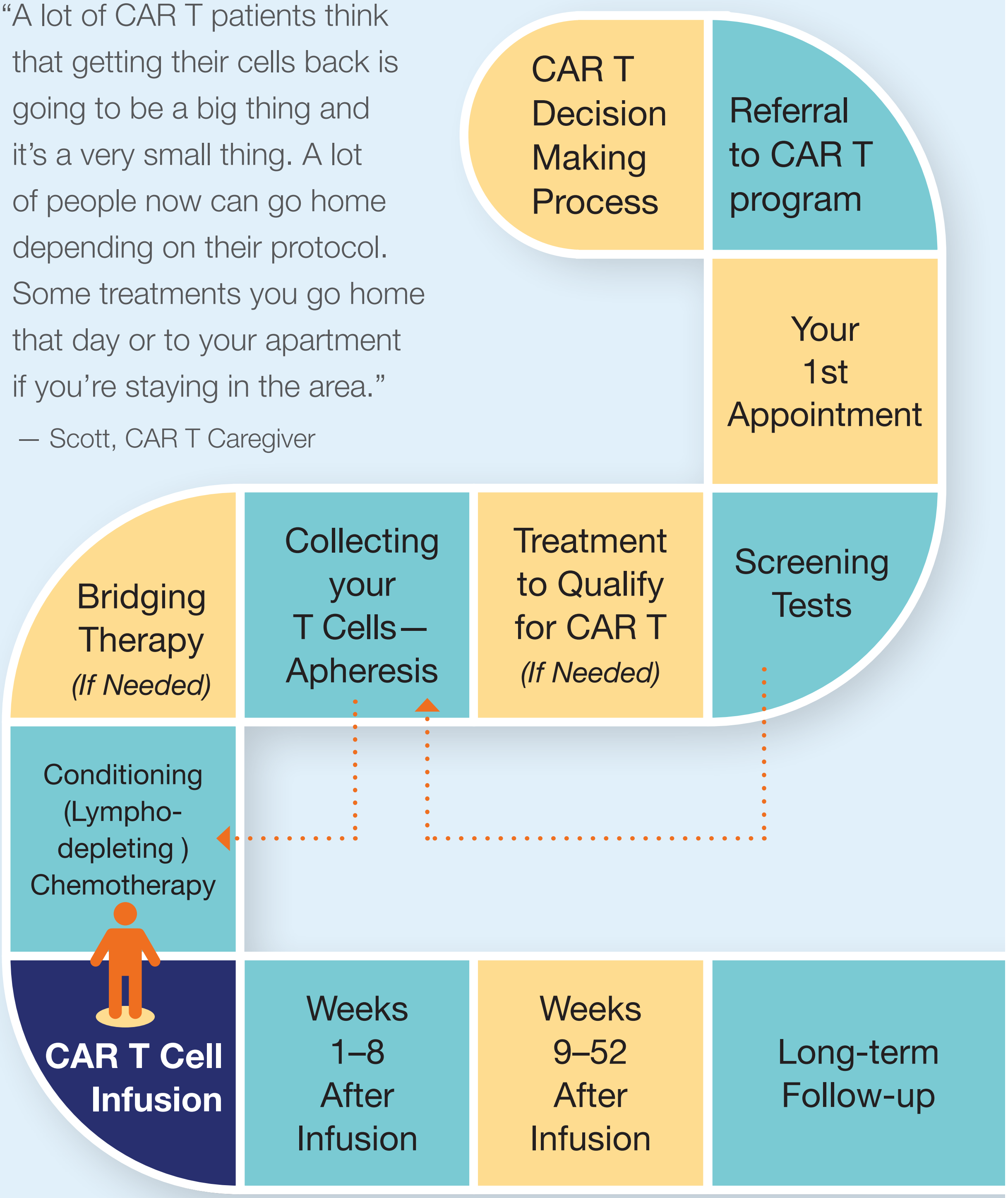
☐ I will stay in the hospital after my infusion for at least __________ days/weeks.

☐ 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

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Collecting your T Cells—Apheresis

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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)* ____ .

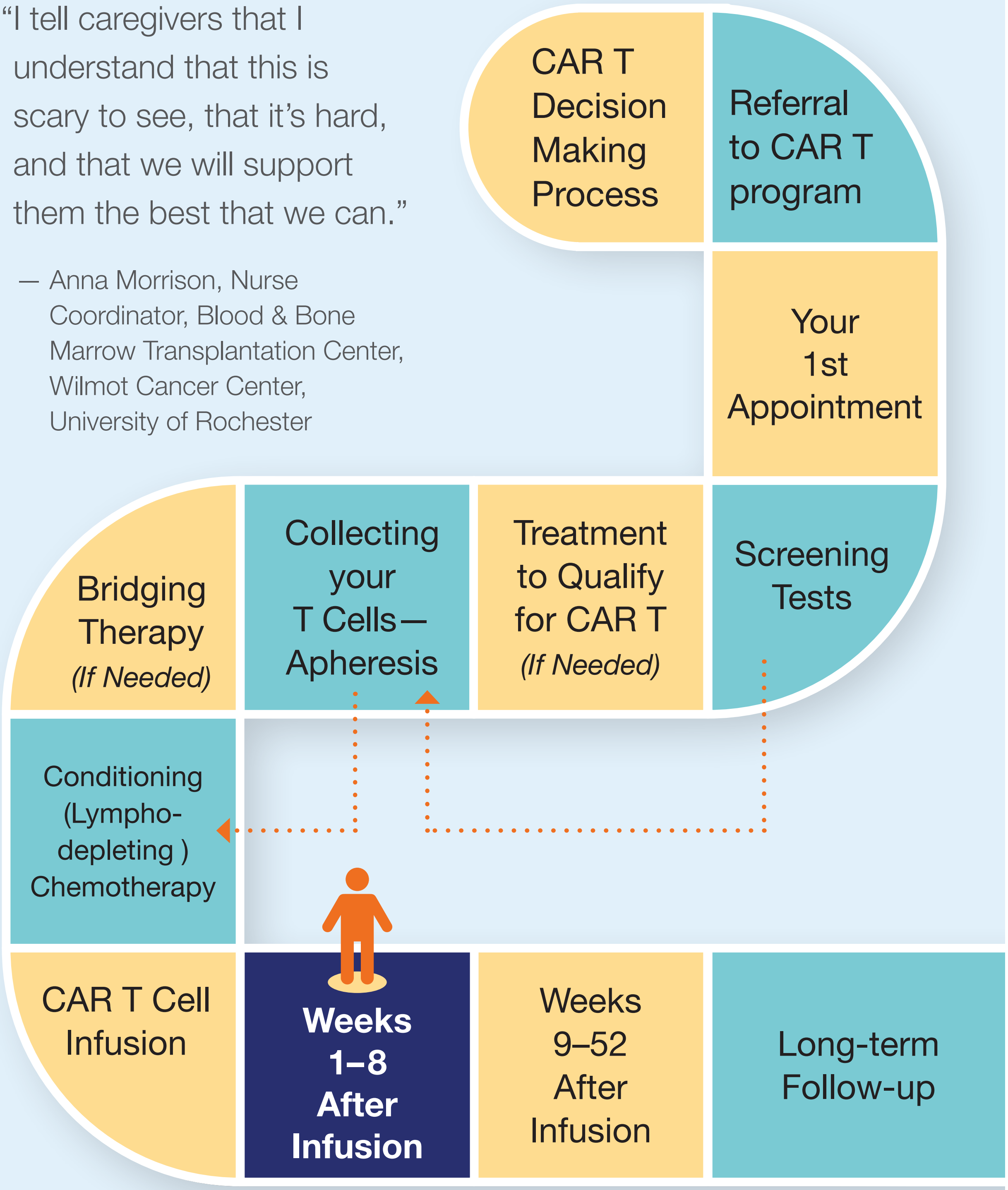
☐ My next appointments are scheduled for *(dates)*:

- ■ ____
- ■ ____
- ■ ____

☐ 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



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 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:

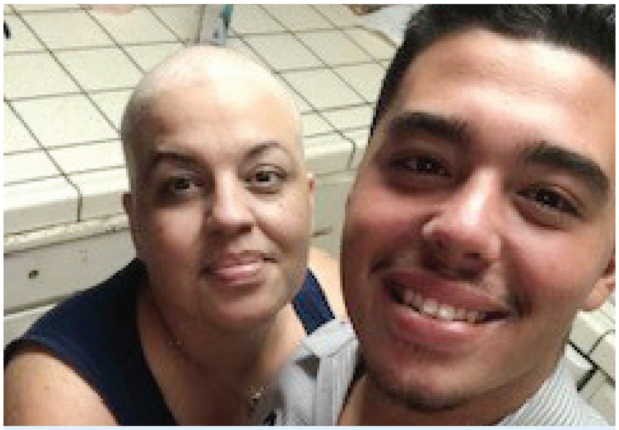
- Washing your hands regularly, for 20 seconds or as long as it takes to sing the "Happy Birthday" song
- Practicing food safety
    - Wash your hands before eating
    - Wash or rinse fruits and vegetables
    - Avoid sharing utensils and drinking containers
    - Avoid eating raw meats and unpasteurized 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)* ____ .

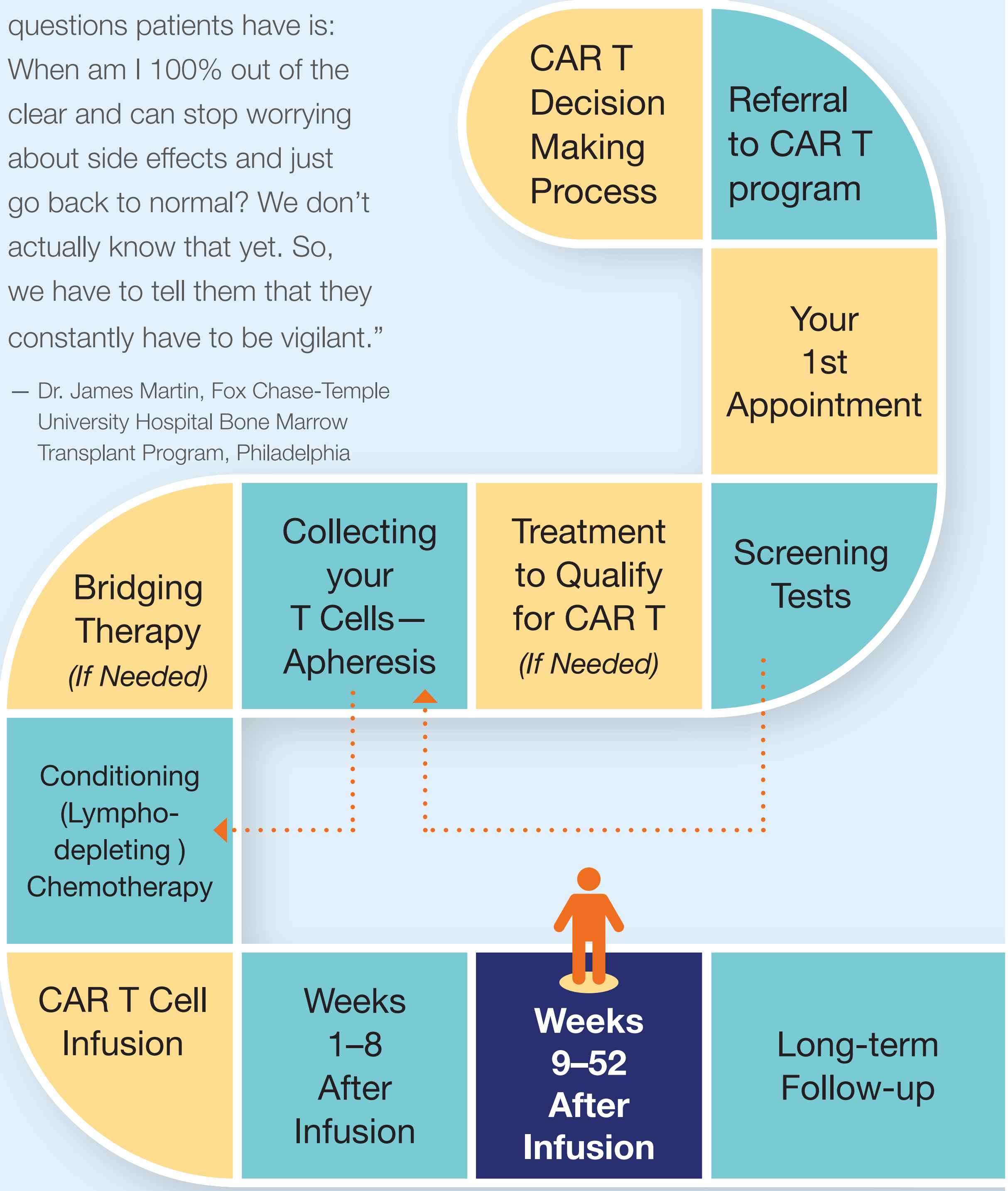
The address for my appointment is ____________________________ ____ .

☐ 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


CAR T Decision Making Process

Referral to CAR T program

Your 1st Appointment

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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.

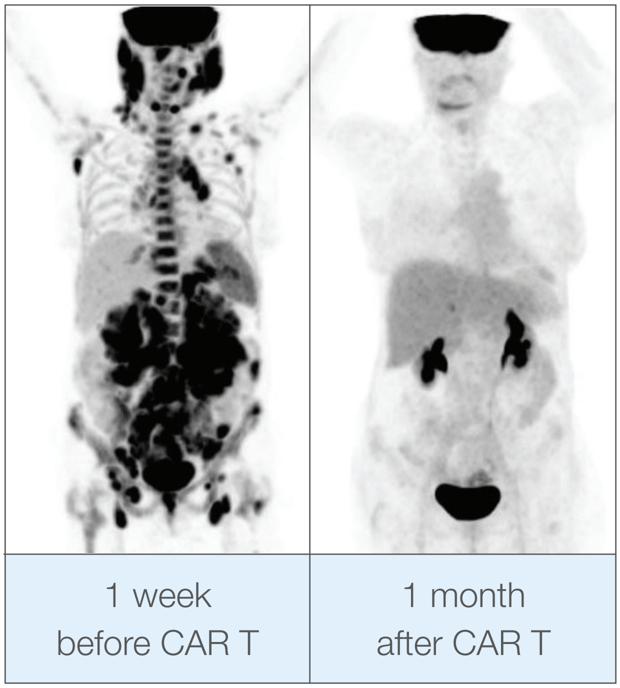
WEEKS 9–52

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.