

Section 3

Resources and Record Keeping

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My Treatment Team Contacts

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

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

MY TREATMENT TEAM CONTACTS

Name & Role _____

Facility & Location _____

I should contact this person if _____

Phone number _____

Email _____

Name & Role _____

Facility & Location _____

I should contact this person if _____

Phone number _____

Email _____

Name & Role _____

Facility & Location _____

I should contact this person if _____

Phone number _____

Email _____

Name & Role _____

Facility & Location _____

I should contact this person if _____

Phone number _____

Email _____

MY TREATMENT TEAM CONTACTS

Name & Role _____

Facility & Location _____

I should contact this person if _____

Phone number _____

Email _____

Name & Role _____

Facility & Location _____

I should contact this person if _____

Phone number _____

Email _____

Name & Role _____

Facility & Location _____

I should contact this person if _____

Phone number _____

Email _____

Name & Role _____

Facility & Location _____

I should contact this person if _____

Phone number _____

Email _____

Resources for Lodging

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

American Cancer Society Patient Lodging

800-227-2345 • www.bit.ly/ACSLodging

Provides lodging at Hope Lodges and hotels across the United States

Hotel Keys of Hope

800-227-2345 • www.bit.ly/KeyOfHope

Extended Stay America has partnered with the American Cancer Society to provide free and discounted hotel room stays to cancer patients receiving treatment away from home

Joe's House

877-563-7468 • www.joeshouse.org/

Online search tool that helps cancer patients and their families find a place to stay when traveling for medical treatment

Resources for Transportation

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

Air Charity Network

877-621-7177 • www.aircharitynetwork.org

Free flights for people who cannot fly commercially because of financial or medical need

Mercy Medical Angels

www.mercymedical.org

Airplane flights, gas cards, and bus and train tickets for patients with financial need

Corporate Angel Network

914-328-1313 • www.corpangelnetwork.org

Free flights for cancer patients on corporate aircrafts

Good Days Travel Assistance Program

877-968-7233 • www.mygooddays.org

Arranges and pays for travel costs for patients with financial need

Leukemia & Lymphoma Society's Travel Assistance Programs

877-557-2672 • www.lls.org/support/financial-support

Financial assistance with travel expenses for blood cancer patients with financial need

American Cancer Society Road to Recovery Program

800-227-2345 • www.bit.ly/ACSTransport

Offers free rides to and from treatment for people with cancer who do not have a ride or are unable to drive themselves

Patient Advocate Foundation

800-532-5274 • www.patientadvocate.org

Their National Financial Resource Directory can help you find national and regional resources for transportation, lodging, and financial assistance

Patient AirLift Services (PALS)

631-694-7257 • www.palservices.org/

Free flights for patients with financial need

Resources for Patients & Caregivers

ONLINE AND TELEPHONE SOURCES OF SUPPORT

CAR T Cancer Support Helpline

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

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

MyLifeLine

www.MyLifeLine.org

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

Leukemia & Lymphoma Society's First Connection Programs

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

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

CAR T-CELL Patients And Carers Facebook Group

www.bit.ly/FBCART

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

Imerman Angels

www.imermanangels.org/

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

Cancer Research Institute ImmunoCommunity

www.cancerresearch.org/patients/immunocommunity

Read real stories of inspiration and lessons learned, or connect directly with ImmunoAdvocates about their experience with immunotherapy treatment, including CAR T.

SUPPORT FOR MAKING TREATMENT DECISION

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

IN-PERSON SUPPORT

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

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

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

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

RESOURCES FOR CAREGIVERS

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

Cancer Support Community

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

Blood & Marrow Transplant (BMT) Infonet

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

CancerCare

- Caregiving Resources: www.cancercare.org/caregiving

Caregiver Action Network

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

Help for Cancer Caregivers

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

Leukemia and Lymphoma Society

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

Lymphoma Research Foundation

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

FINANCIAL & EMPLOYMENT RESOURCES

Triage Cancer

<https://triagecancer.org/> • 424-258-4628

Free education on the practical and legal issues that arise after a cancer diagnosis

Cancer and Careers

www.cancerandcareers.org/en

Empowers and educates people with cancer to thrive in their workplace

Patient Advocate Foundation

800-532-5274 • www.patientadvocate.org

Their National Financial Resource Directory can help you find national and regional resources for transportation, lodging, and financial assistance

Resources for Clinical Trials

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

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

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

Cancer Support Community

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

National Cancer Institute (NCI)

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

American Cancer Society

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

Leukemia & Lymphoma Society

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

Lymphoma Research Foundation

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

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

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

CenterWatch

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

Cancer Research Institute

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

Record Keeping

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

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



YOUR HEALTH CARE PLAN (Including Medicare/Medicaid)

Name _____

Member ID _____ Group Number _____

Address _____

Phone _____ Fax _____

Website _____

Name _____

Member ID _____ Group Number _____

Address _____

Phone _____ Fax _____

Website _____

Name _____

Member ID _____ Group Number _____

Address _____

Phone _____ Fax _____

Website _____

YOUR HEALTH CARE PLAN (Including Medicare/Medicaid)

Name _____

Member ID _____ Group Number _____

Address _____

Phone _____ Fax _____

Website _____

Name _____

Member ID _____ Group Number _____

Address _____

Phone _____ Fax _____

Website _____

Name _____

Member ID _____ Group Number _____

Address _____

Phone _____ Fax _____

Website _____

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

Name _____

Address _____

Phone _____ Fax _____

Website _____

Name _____

Address _____

Phone _____ Fax _____

Website _____

Name _____

Address _____

Phone _____ Fax _____

Website _____

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

Name _____

Address _____

Phone _____ Fax _____

Website _____

Name _____

Address _____

Phone _____ Fax _____

Website _____

Name _____

Address _____

Phone _____ Fax _____

Website _____

AGENCIES & ORGANIZATIONS

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

Name _____

Address _____

Phone _____ E-mail _____

Website _____

Notes _____

Name _____

Address _____

Phone _____ E-mail _____

Website _____

Notes _____

Name _____

Address _____

Phone _____ E-mail _____

Website _____

Notes _____

AGENCIES & ORGANIZATIONS

Name _____

Address _____

Phone _____ E-mail _____

Website _____

Notes _____

Name _____

Address _____

Phone _____ E-mail _____

Website _____

Notes _____

Name _____

Address _____

Phone _____ E-mail _____

Website _____

Notes _____

OTHER IMPORTANT CONTACTS

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

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

OTHER IMPORTANT CONTACTS

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

OTHER IMPORTANT CONTACTS

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

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

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

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

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

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

Name _____

Address _____

Phone _____ E-mail _____

Role _____

CALENDAR

Month _____

MONDAY

TUESDAY

WEDNESDAY

CALENDAR

Month _____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month _____

MONDAY

TUESDAY

WEDNESDAY

CALENDAR

Month _____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month _____

MONDAY

TUESDAY

WEDNESDAY

CALENDAR

Month _____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month _____

MONDAY

TUESDAY

WEDNESDAY

CALENDAR

Month _____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month _____

MONDAY

TUESDAY

WEDNESDAY

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CALENDAR

Month _____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

CALENDAR

Month _____

MONDAY

TUESDAY

WEDNESDAY

CALENDAR

Month _____

THURSDAY	FRIDAY	SATURDAY/SUNDAY	

APPOINTMENT NOTES

Date/time_____

Appointment with_____

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time_____

Appointment with_____

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time_____

Appointment with_____

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time_____

Appointment with_____

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time _____

Appointment with _____

Questions to Ask

Notes

Follow-up / Action Steps

APPOINTMENT NOTES

Date/time _____

Appointment with _____

Questions to Ask

Notes

Follow-up / Action Steps

TREATMENT LOG

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

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

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

TREATMENT LOG

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

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

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

TREATMENT LOG

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

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

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

TREATMENT LOG

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

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

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

MEDICATION LOG

Drug Name Depakote	Prescribed for migraines
Start Date 1/5	Prescriber 1/26
Stop Date Dr. Smith	Side Effects Nausea
Dosage Schedule <input checked="" type="checkbox"/> am <input type="checkbox"/> noon <input checked="" type="checkbox"/> pm <input type="checkbox"/> bedtime <input type="checkbox"/> as needed	
Dosage and Special Instructions	

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule <input type="checkbox"/> am <input type="checkbox"/> noon <input type="checkbox"/> pm <input type="checkbox"/> bedtime <input type="checkbox"/> as needed	
Dosage and Special Instructions	

MEDICATION LOG

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule <input type="checkbox"/> am <input type="checkbox"/> noon <input type="checkbox"/> pm <input type="checkbox"/> bedtime <input type="checkbox"/> as needed	
Dosage and Special Instructions	

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule <input type="checkbox"/> am <input type="checkbox"/> noon <input type="checkbox"/> pm <input type="checkbox"/> bedtime <input type="checkbox"/> as needed	
Dosage and Special Instructions	

MEDICATION LOG

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule <input type="checkbox"/> am <input type="checkbox"/> noon <input type="checkbox"/> pm <input type="checkbox"/> bedtime <input type="checkbox"/> as needed	
Dosage and Special Instructions	

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule <input type="checkbox"/> am <input type="checkbox"/> noon <input type="checkbox"/> pm <input type="checkbox"/> bedtime <input type="checkbox"/> as needed	
Dosage and Special Instructions	

MEDICATION LOG

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule <input type="checkbox"/> am <input type="checkbox"/> noon <input type="checkbox"/> pm <input type="checkbox"/> bedtime <input type="checkbox"/> as needed	
Dosage and Special Instructions	

Drug Name	Prescribed for
Start Date	Prescriber
Stop Date	Side Effects
Dosage Schedule <input type="checkbox"/> am <input type="checkbox"/> noon <input type="checkbox"/> pm <input type="checkbox"/> bedtime <input type="checkbox"/> as needed	
Dosage and Special Instructions	

TEST LOG

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

TEST LOG

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

TEST LOG

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

TEST LOG

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

Name of Test	Date
Notes	

SIDE EFFECTS TRACKER

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

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

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

SIDE EFFECTS TRACKER

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

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

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

SIDE EFFECTS TRACKER

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

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

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

SIDE EFFECTS TRACKER

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

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

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

SIDE EFFECTS TRACKER

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

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

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

SIDE EFFECTS TRACKER

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

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

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