This pamphlet contains important information that you need to know about treatment with CAR T-cell therapy.
What are T-cells?
T-cells are lymphocytes, which are a type of white blood cells. White blood cells fight infection.

What is immunotherapy?
Immunotherapy is a type of cancer treatment that uses the body’s immune system to find and attack cancer cells. CAR T-cell therapy is a type of immunotherapy.
What is CAR T-Cell Therapy?

CAR T-cell therapy uses your own immune system to help fight cancer cells. Your blood is collected through a process called apheresis, sometimes called leukapheresis. This process separates your T-cells from the rest of your blood. The T-cells are then sent to a lab where they are engineered specifically to attack B-cell lymphoma cells. The engineered T-cells are then multiplied and shipped back to the hospital. Back in the hospital, the cells are given back to you through an IV infusion.

CAR T-cell therapy is a complex treatment. It can cause severe side effects. Because of this, it is only given during a stay in the hospital. You will be carefully monitored by your treatment team for any side effects. You will also be told about side effects and how to best care for yourself after you leave the hospital.

The CAR T-Cell therapy process

<table>
<thead>
<tr>
<th>Manufacturing Process</th>
<th>Infusion</th>
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<tr>
<td>Isolate and activate T cells</td>
<td>Infuse same patient with engineered T cells</td>
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<tr>
<td>Engineer T cells with CAR gene</td>
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<tr>
<td>Grow and expand number of T cells</td>
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Image courtesy of Kite, a Gilead company
What can I expect before my infusion?

- You will have a medical and laboratory evaluation with a lymphoma specialist to determine if CAR T-cell therapy is right for you.
- Your lymphoma will be re-staged with a PET-CT scan, if one has not been recently performed.
- You will meet with a social worker to evaluate your psychosocial needs and determine the support we can provide you and your family.
- You will undergo apheresis, a process where your blood is collected and processed to obtain the T-cells. This is an outpatient procedure which lasts about 8 hours (sometimes, a second day of apheresis is needed to collect enough cells). This will take place in the Blood Transfusion Service in the Jackson building.
- Before being admitted to the hospital for your CAR T-cell infusion, you will receive chemotherapy, usually as an outpatient. This chemotherapy is designed to prepare your body for the CAR T-cell infusion.
- Your team will contact you to schedule your chemotherapy appointments and the CAR T-cell infusion admission. There will usually be a few weeks (approximately 21 days) between your T-cell collection and your infusion.
- Your nurse will talk with you about your supportive care team members. You will meet with an Oncology Social Worker. You have access to a Nutritionist, Spiritual Care Provider, or a member of the Parenting At a Challenging time (PACT) team at any time before, during, and after your infusion.
• You will have a central line placed. A central line is a soft plastic tube that is inserted into a vein. You will have either a PICC or a Port-a-cath.

Be sure to ask your treatment team any questions that you have.
How should I prepare? What do I need to know now to prepare for my care after my infusion?

- You should have someone living with you in your house for at least one month after your infusion.
- You should avoid driving or operating heavy machinery for up to 2 months after your infusion.
- You must live within 2 hours drive of the hospital for a month after your infusion.
- You will need to set up a healthcare proxy, if you do not already have one. Your treatment team can provide you with a healthcare proxy form.
- You will receive a patient wallet card and should carry it with you at all times. In the event that you see a doctor you should give this card to them.

What can I expect during my infusion?

On the day you receive your cells:

- Two members of your treatment team will confirm and identify your cells
- Your team will monitor your vital signs (body temperature, pulse rate, breathing rate, blood pressure, and blood oxygen level)
- You will receive medicine to prevent an allergic reaction during the infusion
- You may receive IV fluids
What can I expect after I receive my cells?

- Your hospital stay may range from one week to one month, or potentially longer. The length of stay depends on your body’s reaction to the CAR T-cell infusion and possible side effects.
- You will be monitored closely for side effects, and be treated for side effects if they occur.
- Your vital signs will be checked frequently.
- Your blood will be drawn at least once a day.

What should I do to care for myself after I leave the hospital?

Hand Washing and Infection Control

- Hand washing is the most important way to prevent infections!
- Wash your hands thoroughly with soap (liquid soap in a pump dispenser is recommended), dry them with paper towels, and use a hand-cleaning gel.

Always wash your hands:

- Before eating or making meals
- Before changing your central line dressing
- After using the bathroom
- After touching anything dirty
- Upon entering your house after you have been outside
- Everyone should wash their hands when returning home after work, school, shopping, and so on
- All visitors should wash their hands before visiting with you
Personal Care

- Take a shower or bath every day using mild soap.
- For dry skin, you can use baby oil or a mild skin lotion during or after your shower or bath.
- Do not share towels or facecloths with other family members. Replace used towels and facecloths with clean ones every 4 to 5 days or sooner.
- Use an electric razor for shaving. You can shave with a regular razor when you no longer need platelet transfusions. This is when your platelet count is 50,000 or more.

Mouth Care

- Brush your teeth four times a day. Use a soft-bristled toothbrush and fluoride-containing toothpaste.
- Do not use a mouthwash that contains alcohol if it irritates your mouth.
- You may floss every day unless you are told not to. Do not floss if your mouth, gums, or teeth hurt, have sores, or are bleeding.
- Have a dental exam and cleaning every six months. Check with your team about when you should schedule your first dental cleaning.
- You may need antibiotics before any cleaning or dental work is done.
- Tell your dentist if you have a central line before all dental appointments.
What side effects should I be aware of?

You will be very carefully monitored after your infusion for any side effects. Report any of these side effects to your treatment team right away!

Possible side effects include:
- Cytokine release syndrome (CRS), which can include fevers, low blood pressure, low oxygen levels, fast heartbeat, confusion, and temporary kidney and liver abnormalities
- Neurologic toxicities, which can include confusion, excessive sleepiness, tremor, or seizures
- Decreased blood counts
- Increased risk of infection
- Fever
- Chills
- Swelling in hands, arms, feet, and legs
- Increased risk of bleeding

If you experience any of these side effects after you leave the hospital, call your treatment team right away:
- Fever
- Confusion
- Excessive sleepiness
- Seizures
- Symptoms of infection
- Bleeding

Family members are often the first to notice changes in behavior such as trouble remembering or confusion. Family members should report these changes to your treatment team.

Mass General Cancer Center
Outpatient Phone Number
617-724-4000
Mass General Cancer Center Supportive Care

We are dedicated to treating the whole person. We offer a wide variety of educational and supportive resources to help patients and their families cope with the challenges of cancer treatment.

Oncology Social Work
Oncology Social Workers help patients and their families with many concerns from daily problems to life’s most difficult situations. This is done through counseling, active problem solving, and using hospital and community resources. Social workers are members of your treatment team and are available to you at any time. All social work services are free of charge. A referral is not needed.

Spiritual Care Department
Support is available for persons of all faiths and to those with no religious affiliation. Call 617-726-2220.

The Marjorie E. Korff Parenting At a Challenging Time (PACT) Program
The program provides individual support for cancer patients who have children in their lives. Working hand-in-hand with parents, PACT’s child psychiatrists and child psychologists offer age-specific guidance for helping children cope with a parent’s cancer. Log onto massgeneral.org/cancer/PACT or call 617-724-7272.

Patient Experience Website (Px)
Px is a website that you can save to your phone or personal device, so you have it whenever and wherever you need it. Px provides you with an easy way to connect with information about support and education services, integrative therapies, as well as wayfinding information at the Cancer Center. Log onto cancercenterpx.org.
Key words you may hear from your treatment team:

**Apheresis**  T cells are collected from your blood by apheresis, a process that takes blood from the body and removes one or more blood components such as plasma, platelets, or white blood cells. The remaining blood is then returned to the body.

**Infusion reaction**  An allergic response when the CAR T-cells are being infused into your blood. Your treatment team will monitor your vital signs and labs closely during your CAR T-cell infusion. You will also be given Tylenol and Benadryl before the CAR T-cell infusion to help stop a reaction.

**Tumor Lysis Syndrome (TLS)**  Occurs when tumor cells release their contents into blood, either spontaneously or in response to therapy, leading to lab abnormalities that can progress to kidney damage, irregular heart rhythms, seizures, and death due to multi-organ failure.

**Cytokine Release Syndrome (CRS)**  A serious and common side effect of genetically modified T-cells. This happens when the engineered T-cells bind to cancer cells, become activated and release cytokines into the bloodstream. This causes an inflammatory response resulting in side effects such as fever, nausea, shaking chills, low blood pressure, fast heartbeat, pain, headache, rash, and difficulty breathing. CRS can be a life-threatening complication. Sometimes transfer to an Intensive Care Unit (ICU) is required for closer monitoring.

**Neurotoxicity**  Some patients may develop: confusion, disorientation, trouble speaking, extreme sleepiness, hallucinations (seeing things that are not there), or seizures. Neurotoxicity can be a life-threatening complication. Sometimes transfer to an ICU is required for closer monitoring.
Cancer Center Community Providers

Through our network of collaborations, patients have access to the latest cancer treatments and targeted therapies, early phase clinical trials, timely referrals for second opinions, and improved coordination of care.

Visit massgeneral.org/cancer/community or ask your care team for more information about what services are offered at each site.

Massachusetts General Hospital Cancer Center
55 Fruit Street, Boston, MA 02114 | 877-726-5130

Mass General Cancer Center at Emerson Hospital – Bethke
131 ORNAC, John Cuming Building, Suite 200
Concord, MA 01742 | 978-287-3436

Mass General/North Shore Cancer Center
102 Endicott Street,
Danvers, MA 01923 | 978-882-6060

Mass General Radiation and Hematology/Oncology Services at Newton-Wellesley
Vernon Cancer Center
2014 Washington Street,
Newton, MA 02462 | 617-219-1200

Mass General Cancer Center at Cooley Dickinson Hospital
30 Locust Street, Northampton,
MA 01061 | 413-582-2028

Mass General Hematology/Oncology Service at Martha’s Vineyard Hospital
1 Hospital Road, Oak Bluffs,
MA 02557 | 508-693-0410

Mass General Hematology/Oncology Service at Nantucket Cottage Hospital
57 Prospect Street, Nantucket,
MA 02554 | 508-825-8100

Mass General Radiation and Hematology/Oncology Services at Exeter Hospital
5 Alumni Drive, Exeter, NH 03833
603-580-7336

Mass General Hematology/Oncology Service at Southern New Hampshire Medical Center
8 Prospect Street, Nashua,
NH 03060 | 603-577-3089

Mass General Cancer Center at Mass General Waltham
52 Second Avenue, Suite 1110
Waltham, MA 02451 | 781-487-6100