

#### A CLASS FOR CAREGIVERS:

# Planning for an HCT patient to go Home

Presented by a City of Hope oncology Certified Nurse and Clinical Social Worker

### Ground Rules

- Feel free to ask questions at any time, however, you may also use the chat to type in your questions. Kindly mute your audio if you are not talking and be mindful of background noise.
- This is a safe space. Try your best to keep things confidential.
- Respect one another and do not speak over others. Use kind language.
- To maintain patient confidentiality, we kindly ask that you <u>do not record</u> this session.
- If you have questions or concerns regarding your specific case and would like more guidance, please feel free to reach out to the class hosts and/or your primary social worker at 626-218-2282



#### To help you in your role as a caregiver to:

- Learn about your own self-care needs
- Discover tools and resources to help you
- Get an overview of how to be best prepared to care for patient at home



#### 1. Allogeneic (Allo)/Cord

- o Related or unrelated donor cells
- Allo Recovery time is 100 days from the day of transplant

#### 2. Autologous (Auto)

- o Uses patient's own cells
- Auto Recovery time is 30 days after leaving the hospital

## Caregiver Role – Transplant Patients



- Allo: Be available for 100 days after transplant (or as told by the patient's doctor)
- Auto: Be available for 30 days after patient leaves the hospital (or as told by the patient's doctor)
- Have backup caregivers
- Take the patient to and from appointments (about 2-3 clinic visits per week for allo, about 1 visit per week for auto)
- Help the patient with the things they need to do each day (such as make food, drive, chores at home)
- Help the patient take the right doses of the right medicines at the right times
- Look for changes in the patient's health (miniassessment)
  - Plan to spend the whole day at City of Hope for follow up appointments.

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## Be Safe From Germs and Viruses

#### How to Clean Your Home: Before and After the Patient is Home

- Slowly vacuum carpets a few times. (If the carpet is soiled, it needs to be shampooed and fully dry, before the patient comes home.)
- Dust drapes, blinds and furniture.
- Change filters in air conditioners, furnaces and water filter units.
- Turn off humidifiers.
- Clean all toilets, showers, counters, sinks and tubs
- Do not remodel your home or do major fixes such as breaking down walls or pulling up old carpet. This can cause mold spores to go into the air. If big changes need to be made do them at least 2 weeks before the patient comes home.
- Wash bed sheets once a week. Wash towels daily. Patient should have his/her own towels.
- The patient should sleep in their own bed. If the patient is your partner, it is okay to share the same bed.

Note: Patients should not be the one cleaning the home. Patient may want to leave the room that is being

cleaned.

### How to Set Up Plants

#### Allo: follow for 100 days Auto: follow for 30 days

- Remove fresh or dried flowers from the home.
- Remove house plants from the main living space. It is okay to set them aside in a room away from the patient.
- The patient should not do any gardening post-transplant (ask your doctor when you can start again).
- Speak to your doctor if you have questions about plants at home.



#### How to Care for Pets

#### Allo: Follow for 100 days Auto: Follow for 30 days

#### <u>Do:</u>

- Keep pets as clean as you can.
- You may want to have the pet tested by a veterinarian for any health problems.
- Always wash your hands after touching your pet.
- Keep pet's paws clean. You may use a mixture of half vinegar and half water to soak/clean the paws, or hypoallergenic baby wipes. Keep claws short with smooth edges (ask your groomer about grinding instead of clipping).
- Talk to your doctor about keeping your pet either indoors or outdoors.
- Talk to your doctor if you have multiple pets.

#### Do not let the patient :

- Clean cat litter boxes, bird cages, fish tanks
- Pick up dog waste
- Touch reptiles (such as snakes, lizards, turtles)
- Sleep with their pet

## Mask Wearing

<u>Allo</u> transplant patients will need to wear a mask for the first **100 days** after transplant when not at home.

<u>Auto</u> transplant patients will need to wear a mask when at the hospital and as told by the doctor.

- Adults: 30 days after discharge.
- Pediatrics: 30 days after transplant.
- Wear a mask when at the hospital or clinic. The mask patients must wear is called N-95. (You can buy them online or ask medical team.)
- Stay away from crowds and people who may be sick.



#### Vaccines

#### Allo: 1 year after the transplant.

Auto: Your doctor will advise you.

#### Before that, the patient should:

- not get any live vaccines
- stay away from people who got the Sabin oral polio vaccine or yellow fever vaccine for one month
  - For children in the family, we recommend the inactivated Salk parenteral vaccine
- do not go near people that are vaccinated with a live vaccine (through the nose). Ask a doctor how long it takes for the person to be clear of the virus before you are near them.
- always check with your doctor before receiving any vaccines

### How to Keep Safe from Germs and Viruses

#### Remind patients, family and friends to wash hands in the right way.

(See Safe Care Clean Hands booklet)



https://youtu.be/eZw4Ga3jg3E

## How to Care for the Body and Mind

## Mini Assessment Overview

#### MINI ASSESSMENT: A CHECKLIST FOR CAREGIVERS

#### MENTAL

□ Slow to answer (Ask things like: Can a stone float on water? What day, month and year is it? In what hospital do you get care? Ask short-term questions like: What did you eat yesterday?)

□ Anxious (feeling nervous, can't feel calm, constant worry)

Depressed (tearful, unable to enjoy things that they usually can enjoy)

□ Not making connections (may be foggy, cannot answer easy questions or follow verbal cues)

Having changes in mood, energy levels, physical activity, etc.

□ Having disturbed sleep (due to worry or anxiety)

#### NUTRITIONAL

Any changes in appetite?
Any changes in calorie consumption?
Eating at least 1500 calories

Drinking at least 8 cups of liquid (water, juice, tea, soup, etc.)

#### PHYSICAL

□ Check body temperature. Use a digital thermometer on forehead, ears or mouth in the morning and at night. Call if it is higher than 100.4° F.

Look for rashes, swelling, bumps, bruises, lesions or skin color changes from head to toe.

 $\Box$  Look for redness, white patches or lesions in the mouth.

Check urine output and bowel patterns (do this before shower).

□ Has disturbed sleep (due to changes in the body)



### Mini Assessment: Mental

#### Do this twice a day (morning and night).

It should take 5 minutes. If something changes or is abnormal, write it down and call the **Nursing Triage Call Center at (626) 218-7133**.

## Mental: This is done to see changes in mental health that would also tell us if there is a change in the body. <u>Is the patient.</u>

- □ Slow to answer (Ask things like: Can a stone float on water? What day, month and year is it? In what hospital do you get care? Ask short-term questions like: What did you eat yesterday?)
- Anxious (feeling nervous, can't feel calm, constant worry)
- Depressed (tearful, unable to enjoy things that they usually can enjoy)
- □ Not making connections (may be foggy, cannot answer easy questions or follow verbal cues)
- □ Having changes in mood, energy levels, physical activity, etc.
- □ Having disturbed sleep (due to worry or anxiety)

## Mini Assessment: Nutritional

#### Do this twice a day (morning and night).

It should take 5 minutes. If something changes or is abnormal, write it down and call the **Nursing Triage Call Center at (626) 218-7133**.

**Nutritional**: This is done to keep the patient healthy by getting enough food to have the energy to do normal daily activities.

□ Any changes in appetite?

- □ Any changes in calorie consumption?
- □ Eating at least 1500 calories?

□ Drinking at least 8 cups of liquid (water, juice, tea, soup, etc.)

## Mini Assessment: Physical

#### Do this twice a day (morning and night). It should take 5 minutes.

If something changes or is abnormal, write it down and call the **Nursing Triage Call Center at (626) 218-7133**.

*Physical*: This is done to find early signs of fever, infection, and GVHD.

- Check body temperature. Use a digital thermometer on forehead, ears or mouth in the morning and at night. (Day Hospital patients should check every 4 hours when away from the hospital.) Call if it is higher than 100.4°F.
- Look for rashes, swelling, bumps, bruises, lesions, or skin color changes from head to toe.
- □ Look for redness, white patches, or lesions in the mouth.
- □ Check urine output and bowel patterns. (do this before shower)
- □ Has disturbed sleep (due to changes in the body)

## Body: Stay Alert for Fever

- We recommend taking the patient's temperature twice a day and whenever the patient is not feeling well.
- A fever is a temperature of 100.5F or higher.
- It can be a sign of infection.



## Body: How to Keep Skin Healthy

Tips to keep patient's skin strong and safe from infection:

- Stay out of the sun as much as you can. Wear hats, long sleeves, pants, and sunglasses.
- Use an umbrella when out in the sun.
- Wear sun block (SPF 30+) even in the car and on cloudy days.
- Keep showers less than 10 minutes and use warm water.
- Use hypoallergenic and unscented moisturizers such as Cetaphil, Cerave, Aveeno, Aquaphor, Vaseline or other lotions.
- Use skin moisturizers after bathing and as needed.
- Report any rashes, redness or skin changes to your medical team.

# Graft Versus Host Disease (GVHD)

## What is Graft Versus Host Disease?

#### For ALLO transplant ONLY:

An allogeneic transplant uses blood-forming cells donated by someone else. GVHD happens because the donated cells (the graft) and the patient's cells (the host) are not the same. The new cells from a donor might attack the patient's cells because they see that they are not the same.

It is a common, and sometimes serious, side effect of an allogeneic transplant.

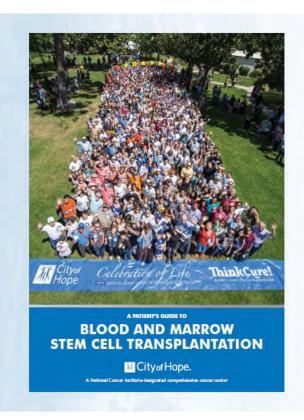
GVHD can range from mild to severe.

#### GVHD: Acute and Chronic (For Allo Transplants Only)

About 80% of <u>allo patients</u> will have some GVHD.

- <u>Acute</u>: Day 7-100
- <u>Chronic</u>: From day 80 and on

   More likely to get chronic
   GVHD if you've had acute
   GVHD.



Check your transplant binder for more information or visit www.cityofhope.org/gvhd.

## Signs and Symptoms of GVHD

	Skin	GI Tract	Liver	Lungs	Eyes
Acute	<ul> <li>Redness of palms of hands and soles of feet</li> <li>Rash over parts of the body</li> <li>Sensitive, itchy or dry skin</li> </ul>	<ul> <li>Diarrhea</li> <li>Nausea</li> <li>Loss of appetite</li> <li>Abdominal cramps</li> </ul>	<ul> <li>Enlarged liver</li> <li>Increased liver function test* (bloodwork)</li> <li>Abdominal tenderness</li> </ul>		
Chronic	<ul> <li>Darkened and dry skin</li> <li>Peeling of skin</li> </ul>	<ul> <li>Diarrhea</li> <li>Weight loss</li> <li>Difficulty eating or loss of appetite</li> <li>Dry mouth</li> </ul>	<ul> <li>A gradual increase in liver function test* (bloodwork)</li> <li>Enlarged liver</li> <li>Abdominal tenderness</li> <li>Yellowish color of skin and eyes</li> </ul>	<ul> <li>Hard to take deep breaths</li> <li>Shortness of breath</li> </ul>	<ul> <li>Dry eyes</li> <li>Sensitivity to light</li> </ul>

\*Liver function tests- blood tests that show how the liver is working

## Lower the Risk of Getting GVHD

#### Take your medicines

- It's important to take your medicines on schedule, even if you are feeling healthy.
  - Common immunosuppressants: Sirolimus, Tacrolimus, Cyclosporine, and Cellcept as prescribed.
- Call your doctor right away if you can't take the medicine for any reason.
- Even with medicine, some people still get GVHD.

#### Watch for early signs and tell your doctor.

- Do not brush off the early signs of GVHD.
- Early treatment of GVHD, infections and other side effects from treatment can make a big difference in your long-term recovery.

#### Protect yourself from the sun

• See "How to Keep Skin Healthy"

# Ways to Stay Healthy

### Body: Fitness Goals

#### Help the Patient Reach Fitness Goals

- The patient's Rehabilitation Team of Physical and Occupational Therapists (PT/OT) will give you a home exercise program to follow.
- Daily exercise can help keep the heart and lungs strong, keep muscles from getting weak, lower the chance of injury and lessen the chance of a fall.
- If the patient is too tired to do any exercise, at least have them sit up in a chair for a few hours each day.
- Outpatient PT/OT may be needed if the patient is not strong enough or finds it too hard to do daily activities at home.
  - If you have questions, call PT/OT at x63328 or (626) 218-3328

## Food Safety Guidelines

## Food Safety



- Getting sick from eating is caused by bacteria, viruses or parasites that can be in food.
- For the patient, these illnesses can be serious.
- Patient cannot eat out.
- Follow your doctor's advice if it differs.

## Food Safety Summary

- 1. <u>CLEAN</u>: Wash hands, utensils, and cutting boards before and after you touch raw foods.
- 2. <u>SEPARATE</u>: Keep raw meat and poultry apart from foods that won't be cooked.
- **3.** <u>**COOK**</u>: Use a thermometer and check the temperature chart (below).
- 4. <u>CHILL</u>: Chill leftovers and takeout foods within 2 hours and keep the fridge at 40° F or below.



Clinical Nutrition Services:

(626) 218-2108

## Food Guide

Type of Food	Safe Foods to Eat	Foods to Avoid
Meat, Deli and Poultry	<ul> <li>✓ Meat or poultry cooked to safe minimum internal temperatures</li> <li>✓ Hot dogs, lunch meats, or deli meats reheated to steaming hot or 165° F</li> </ul>	<ul> <li>Raw or undercooked meat or poultry</li> <li>Hot dogs, deli meats and luncheon meats that have not been reheated</li> </ul>
Fish and Seafood	<ul> <li>✓ Previously cooked seafood heated to 165° F</li> <li>✓ Canned fish and seafood</li> <li>✓ Fish cooked to safe minimum internal temperatures</li> </ul>	<ul> <li>Any raw or undercooked fish or shellfish, or food containing raw or undercooked seafood e.g. sashimi (found in sushi, ceviche, etc.)</li> <li>Refrigerated smoked fish</li> <li>Partially cooked seafood, e.g. shrimp and crab</li> </ul>
Milk	✓ Pasteurized milk	🗵 Unpasteurized (raw) milk
Cheese	<ul> <li>✓ Cheeses that are clearly labeled "made from pasteurized milk," such as:         <ul> <li>Hard cheeses</li> <li>Processed cheeses</li> <li>Cream cheese</li> <li>Mozzarella</li> <li>Soft cheeses</li> </ul> </li> </ul>	<ul> <li>Soft cheese made from unpasteurized (raw) milk, such as:</li> <li>Feta</li> <li>Brie</li> <li>Camembert</li> <li>Blue</li> <li>Queso fresco (Mexican cheese type)</li> </ul>

## Food Guide

Type of Food	Foods Allowed	Foods to Avoid
Eggs	<ul> <li>At home:</li> <li>✓ Use pasteurized eggs/egg products when preparing recipes that call for raw or undercooked eggs</li> <li>✓ All other unpasteurized eggs need to be fully cooked</li> <li>When eating out:</li> </ul>	Foods that contain raw or undercooked eggs, such as: ⊠ Homemade Caesar salad dressings ⊠ Homemade raw cookie dough ⊠ Homemade egg nog
	✓ Ask if pasteurized eggs were used	
Nuts	✓ Roasted or cooked nuts	🗵 Raw nuts
Fruits and	✓ Washed fresh fruits and vegetables,	Raw sprouts (alfalfa, bean, or any other
Vegetables	including salads	sprout)
	✓ Cooked sprouts	☑ Unwashed fresh fruit and vegetables,
	✓ Cooked, frozen or canned fruits and	including lettuce/salads
	vegetables	Fruits or vegetables that have bruises, visible
	✓ Canned or pasteurized fruit or vegetable	mold, and/or soft spots
	juices	☑ Unpasteurized fruit or vegetable juices
Pates	✓ Canned or shelf-stable pates or meat	Unpasteurized, refrigerated pates or meat
	spreads	spreads
Honey	✓ Honey that clearly states that it has been	Unpasteurized honey
	"pasteurized"	
	✓ Baked goods, cereals, snacks and other	
	foods containing honey that have been	
	pasteurized	
	✓ Cooked non-pasteurized honey	

# Medication Management

### How to Take Medication at Home

- Know the reason for the medication and what it does.
- Make a medication calendar or diary. Medication management apps can also be used.
- Use a medication pill box.
  - Have a pill box with 4 doses per day
  - Do not fill more than 4 days out at a time
- Store medications the right way and in a safe place.
- For ALLO patients on clinic days do not take immunosuppressant medication until after lab testing.



#### APPS TO HELP YOU MANAGE YOUR **MEDICATIONS**

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#### CAREZONE

#### COST Free

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Care Zone helps organize health information as well as access health services. You can scan your medications and set up reminders for when to take your pills. You can also keep track of important health vitals that can be shared with others.



It can be hard to keep track of the medicines you need to take while you are getting cancer treatment. You may have several pills that must be taken at different times or in different ways, which can add to the stress of cancer treatment.

It is important to take the right dose of the right medicine. These are a few apps that can be used to help you manage your medications.

This is for information purposes only. City of Hope has no affiliations with the developers of these apps and has no preference over one versus the others.



#### MEDISAFE MEDICATION JD MANAGEMENT

COST Free

Upgrades: \$4.99 per month or \$39.99 per year

Medisafe gives medication and refill reminders, as well as provides drug interaction warnings and the ability to do family scheduling.

This app also lets you share your medication information with your health care team.





#### PILL REMINDER

#### COST Free

1

Upgrades: \$1.99 one time payment for full version

Pill Reminder helps you remember to take your medications at the right time. It will allow you to make any type of regular reminder and will keep track of the amount of medication left. There is also an appointment reminder option.





#### **ROUND HEALTH**

#### COST Free

Round Health helps users remember to take their pills. The app will not only remind users to take their medications, but can also keep track and send reminders of their supplements.





### Let Your Medical Team Know If...

- There is a bad reaction (for example, a rash, sudden fever, headache or nausea. Check the information that came with your medicine.)
- □ A dose is missed
- □ Any nutritional supplements/vitamins, or herbal medicines or cannabis are used.
- □ There is any trouble getting the medicine that you were prescribed.

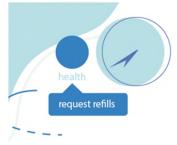
For any of questions or concerns, call or use MyCityofHope to contact your medical team. You will be given this information before leaving the hospital.

# City of Hope Contacts

If you have any questions or need to report a problem Monday-Friday from 8am - 5pm	Call 626-256-HOPE (4673), dial "0" and ask for your doctor's office
Weekends, holidays, or after 5pm	Call 626-256-HOPE (4673) Dial "65200"
City of Hope Prescription Refill/Renewal Line	626-301-8304
City of Hope 24-hour Nursing Triage	626-471-7133

• Keep these on your phone and in your home (such as on your refrigerator)

# MyCityofHope



### With MyCityofHope, you can:



### Request appointments.

Request your next appointment and view details of past and future appointments.



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Ask for prescription refills. Send a renewal request for any of your refillable medications.

View After Visit Summaries. View your After Visit Summary and clinician notes.

#### sh. Access most test results.

No more waiting for a phone call or letter. View your results for most tests online at your convenience.

Communicate with your care team. Email your care team to get answers to medical questions without multiple telephone calls or unnecessary appointments.

Pay bills online.

Check and pay your bills from home.

### Share with people

#### 202 Give friends and family access.

Give access to your family and caregivers who help you with your health care needs.





Access information about your visits or send it to someone else.

### Connect with hospitals and doctors



**Connect to Hope Virtual** appointments.

Connect with your City of Hope provider via a scheduled televisit appointment from home or wherever is most convenient for you.

#### Give one-time access 米 with Share Everywhere.

Share your information with just about anyone, like a social worker or a school nurse.

### Connect your accounts.

Combine your medical records from multiple health care providers that use the MyChart technology, allowing you to see your records in one place.

#### Allow other hospitals and doctors to access your information. 500

Give permission for a different health care provider to see your information.



CitvofHope.org





### *My*City<sub>of</sub>Hope

MyCityofHope is a secure online portal that puts your medical information at your fingertips.

# When to Call Nursing Triage

### Report these symptoms:

- Vomiting
- Diarrhea
- Bleeding that does not stop
- Rashes
- Cannot drink fluids
- Uncontrolled pain

### Watch for signs of infection:

- A fever of 100.5°F (38°C) or more
- Shaking and chills after flushing your catheter
- Chills without fever
- Lasting cough with or without phlegm
- Coughing or sneezing
- Pain, swelling or redness of the throat

## When to Call 911

Call 911 right away if patient has <u>any</u> of these symptoms:

- Very strong chest pain
- Trouble breathing
- Bleeding that will not stop
- Unconsciousness
- Serious injuries or burn



- Signs of shock: rapid weak pulse, cold pale clammy skin, confusion, rapid breathing
- Slow to answer
- Signs of a stroke such as change in mental state, trouble speaking, sudden severe headache, numb feeling in face, arms or legs

# Navigating Transplant with a Helping Hand

## Clinical Social Work

- Cancer and other serious illnesses affect the whole family in emotional, social and practical ways.
- It is common for patients, families and friends to experience distress (worry, anxiety, depression, fear, uncertainty).
- Clinical Social Workers can help you identify and reduce sources of distress, offer counseling support, and link you to useful resources in the community.

To reach your Clinical Social Worker, call the Division of Clinical Social Worker at 626-218-2282.

Location: Duarte campus, Main Medical, down the hall from pharmacy.

# Day of Discharge

- Getting ready to leave the hospital can be emotional.
- There may be changes to the plan as your healthcare team works to ensure a safe discharge.
- You will meet with multiple members of the multidisciplinary team to help you prepare for discharge.
- Readmissions do occur and we are here to support you.



## Communication

## Medical Team

- o Ask them how best to communicate between appointments.
- Keep a notebook with questions/concerns.
- If you are unable to accompany patient, ask to be conferenced in for the appointment.

# Friends/Family

- Communicating with friends and family
  - o Choose a family spokesperson
  - o Use social media
  - o Access websites such as 'Caring Bridge' or 'Lots a Helping Hands'

Relationships can change when a person goes through a major medical event, and this is not your fault. Not all help is helpful. It's okay to let someone know if what they're doing is not meeting your need.

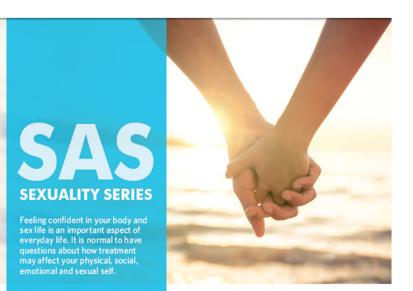
# Intimacy and Sexual Activity

- You may notice changes in your relationship and/or sexual desire. This is a normal part of recovery.
- It is okay be close to your loved one. We encourage you to find ways to connect.
- Communicate with your medical team about when sexual activity can begin. It remains important to practice safe sex.
- If you experience any pain during sex or other unusual problems, bring this up with your medical team.

## Resources

- The Positive Image Center at City of Hope may have products that can help with sex and intimacy.
- American Cancer Society:
  - o Sexuality for the Man with Cancer
  - Sexuality for the Woman with Cancer

### (Info sheets available in the Biller Patient and Family Resource Center)



### What is SAS?

SAS stands for Self-esteem, Appearance and Sexuality. It is a two day class that addresses common questions and concerns related to body image, self-esteem and sexuality, which may be affected by cancer and treatment.

### What will I learn in SAS?

- · How cancer may impact your sex life and body image during and after treatment
- Practical strategies to overcome challenges to intimacy, sexual activity and other day-to-day activities
- · Resources at City of Hope and within your community that can help you feel and look your best

### Request a referral to Occupational Therapy

## Practice Self Care



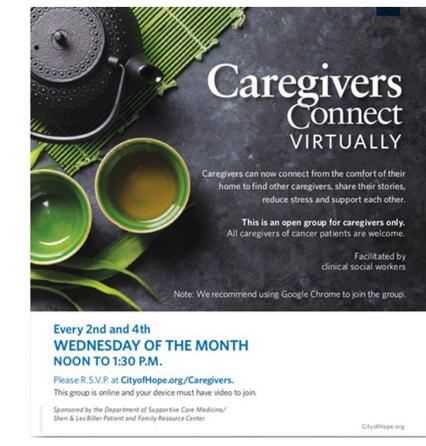
### Ways to Recharge:

- Breathe, really breathe...
- Take a walk, change your environment
- Take a break
- Do a self-massage
- Take a five-minute shower
- Hold your pet
- Spend time with family and friends
- Laughter and humor
- Listen to music and just sing

# Support at City of Hope

There are support groups available at City of Hope and in your community. Here are a few agencies to consider when accessing support:

- Be the Match
- Leukemia and Lymphoma Society
- American Cancer Society
- Cancer Support Community
- Cancer Care



For more information visit the Biller Resource Center at City of Hope or call 626-218-2273. You may also reach out to your primary Clinical Social Worker.

## How to Access Class Material

### Website: www.cityofhope.org/HCTDischargeClass

 You may access a virtual recording of the English and Spanish classes, download the class slide deck, and view caregiver materials.

**CCTV:** Recordings of the English and Spanish classes are also available on inpatient TVs. This allows patients and caregivers to watch the recording during hospital admission.

QR Code:



### How to Access the HCT Caregiver Class on Your TV

Patient Instructions

#### Quick steps:

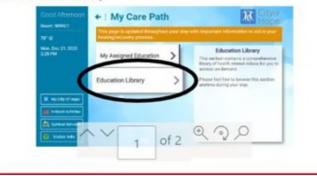
- 1. From Main Menu, select My Care Path.
- 2. Select Education Library.
- 3. Select Safe Care.
- 4. Select HCT Discharge Class for Caregivers. Available in English and Spanish.

#### Full Tip Sheet

1. From Main Menu, select My Care Path.



2. Select Education Library.



# Thank you!

