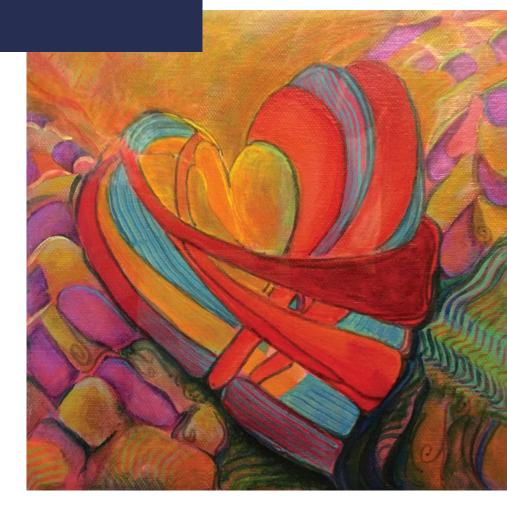
UCSF Helen Diller Family Comprehensive Cancer Center

Information, Support & Resources



This guidebook would not have been possible without the contribution of numerous individuals throughout the cancer center, including staff, doctors, and nurses.

Aspecial thanks goes to members of the Patient and Family Advisory Council for their contribution.



## Introduction: How to Use This Guide

You have received this guidebook because you have an appointment at the UCSF Helen Diller Family Comprehensive Cancer Center. This does not mean that you have a confirmed diagnosis of cancer, but it does mean that you are seeing one of our specialists for treatment or advice.

This guidebook provides an overview of our cancer services and programs, as well as tips and suggestions to help you manage your care. As you read through this guide, feel free to highlight sections or jot down notes in the last pages of the guidebook, which have been left blank for your use.

Bring this guidebook to your next appointments and use it as a reference to help you navigate your care and access our services and programs.



The artwork used in this guidebook was created by patients, families, caregivers, and medical staff in Art for Recovery, a program at the UCSF Helen Diller Family Comprehensive Cancer Center. Chank you for partnering with UCSF for your care. We understand that dealing with a cancer diagnosis, medical tests, and appointments may feel overwhelming. We know there is a lot of information to absorb and many decisions to make. This guidebook is designed to serve as a road map to our services and to help guide you through treatment. We hope that this information will help you connect to the people and programs that will best serve you as your needs change.

The UCSF Helen Diller Family Comprehensive Cancer Center holds the highest designation possible from the NIH National Cancer Institute and has been consistently ranked as the top cancer center in California for several years. UCSF is known for its cutting-edge research and targeted cancer treatments to improve outcomes and quality of life. These breakthrough

advances include immunotherapy that harnesses the body's own immune system to fight cancer, treatments that target the molecular biology of cancer cells, and minimally invasive surgical procedures. We are deeply committed to the community we serve and to making life better for patients, families, and our neighbors.

The exemplary care we provide is possible because of the exceptional UCSF researchers, physicians, nurses, and staff who come together every day to serve our patients and families. I sincerely hope that the care you



receive exceeds your expectations. If there is any way in which we can improve your experience, please let us know by sharing your suggestions and feedback at ucsfhealth.org/CC-ImprovementIdeas.

Finally, I'd like to acknowledge the Patient and Family Advisory Council members whose ideas, suggestions, and language are woven into this guidebook.

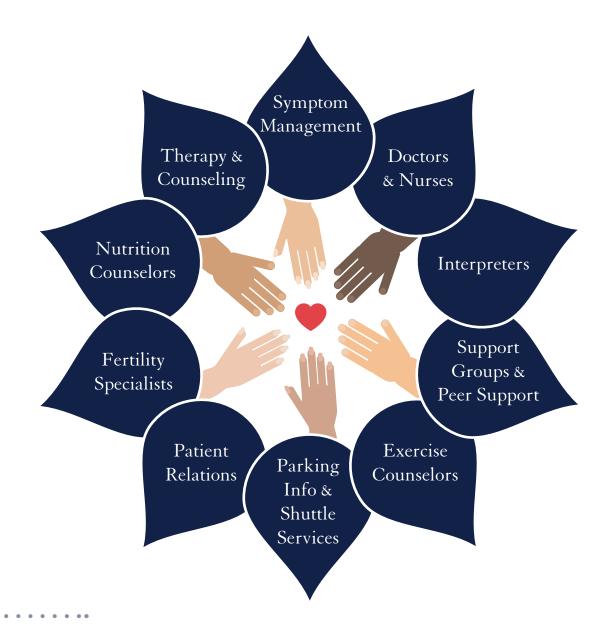
Sincerely,

Alan Arl

*Alan Ashworth, PhD, FRS President, UCSF Helen Diller Family Comprehensive Cancer Center* 



There are many people and services here to help you navigate your cancer journey.



ancer is a reminder that our life can be derailed and can wrest control away from us. Learning to befriend uncertainty, to feel comfortable in that gray area of not knowing, can help manage anxiety.

When feeling overwhelmed by all the unknowns, it is helpful to focus on the present and to rest in the moment-to-moment experience of breathing.

Befriending uncertainty means living life knowing that it is finite, while recognizing that no one knows with certainty how long we have to live. And it is this realization that makes each day precious and worth living as fully as possible.

# Patient and Family Guide to Cancer Services at UCSF

Information, Support, and Resources



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An online PDF of this guidebook can be found at cancer.ucsf.edu/Guidebook

## Important UCSF Phone Numbers



## UCSF Operator 415-476-1000

Directs you to UCSF staff departments, and patients in the hospital.

For those who would prefer to speak a language other than English, Interpreters are available for most numbers. To speak with an interpreter, say your name, phone number, and the language you speak.

> Information about all the support services listed below can be found at cancer.ucsf.edu/support

Important UCSF Phone Numbers	
Advance Care Planning and What Matters Most workshops	415-509-8645
Art for Recovery	415-885-7225
Cancer Clinical Trials	877-827-3222
Cancer Genetics and Prevention Program	415-885-7779
Cancer Immunotherapy Program	415-353-2051
COVID-19 Coronavirus information and hotline	415-514-7328
Exercise Class: - Core and More - Yoga	415-514-6430 415-353-7718
Exercise Counseling	415-502-5547
Fertility Preservation Program	415-353-9115
Financial Services- Understanding medical bills arranging payment plans or getting financial assistance	866-433-4035 Or through MyChart messaging

Important UCSF Phone Numbers	
Friend to Friend Specialty Shop	415-353-7776
Imaging Library/Film Library (to obtain CDs with images from Radiology)	415-353-1640
Improvement ideas	
Infusion Center	
- Mission Bay and Mount Zion	415-353-7155
- Parnassus	415-353-2272
Interpreting Services	Call the Practice providing your care
Knitting Gathering	415-885-3693
Lodging Resources (Short Term)	Discuss with your social worker or call 415-353-4762
Medical Records (to obtain copies of your medical records)	415-353-2221
Medication Disposal Information	
Meditation and Guided Imagery	415-885-3693

Important UCSF Phone Numbers		
MyChart Assistance	415-514-6000	
Neuro-Oncology Gorden Marray Caregiver Program	1 0	
New Patient Orientation (online)		
Nutrition Counseling	415-502-5547	
Nutrition Workshops and Events	415-885-3693	
Osher Center for Integrative Medicine	415-353-7700	
Parking: Available spaces Mission Bay	park.ucsf.edu	
Parking Information		
- Mission Bay	415-476-1511	
- Mount Zion	415-514-8935	
- Parnassus	415-476-2566	
Patient and Family Cancer Support Center	415-885-3693	

# Important UCSF Phone Numbers

Patient Cost Estimates Program (Getting a cost estimate for care)	844-678-6831 (844-6-QUOTE-1) PatientEstimate@ucsf. edu
Patient Relations Office	415-353-1936
Patient Support Corps (help with notetaking)	415-476-6004
Peer Support Program	415-885-3693
Psycho-Oncology Service	415-353-7019
Radiology scheduling (Imaging and scans)	415-353-3900 415-353-7175
Radiology/imaging/Film Library	415-353-1640
Security	415-885-7890
Social Work	415-353-4762
Spiritual Care	
- Mission Bay	415-514-4200
- Parnassus and Mount Zion	415-353-1941

Important UCSF Phone Numbers		
Stop Smoking Programs	415-885-7895	
Support Groups	415-885-3693	
Survivorship Wellness Group Program (Post Treatment)	415-353-3931	
Symptom Management Service (SMS)	415-885-7671	
Thank and Recognize Exceptional Staff		
UCSF500 Gene Panel Test	ccgl@ucsf.edu	
Video Visit Instructions	415-514-6000	
Wheelchair Escort		
- 400 Parnassus	415-353-1664	
- 505 Parnassus	415-353-1188	
- Mission Bay	415-476-1540	
- Mount Zion	415-885-7255	
Workshops, Events, and Retreats	415-885-3693	

## What is Cancer?



"Getting cancer has made me realize that every day I have is precious. I feel I owe it to myself to make the most of this incredible gift of life."

~ Kelley

Cancer is caused by an overgrowth of abnormal cells. These cells divide and multiply in an uncontrolled fashion and can spread to other parts of the body. When damaged cells travel to another part of the body and invade healthy tissue, it is called a metastasis.

The type of cancer you have is based on where the abnormal cells originate in the body. If the cancer cells start growing in the breast, it is called breast cancer, even if those cells spread to other parts of the body, such as the bones or liver.

Cells can become cancerous for many different reasons, including genetic inheritance (where the trait is passed on from one generation to the next), exposure to cancer-causing chemicals, as well as other factors, which are still being studied. The goal of treatment is to destroy, remove, or control the cancer cells. Some of the most common types of treatment include:

- Surgery, which involves removing the cancer cells
- **Chemotherapy**, which uses medications to destroy cancer cells that may be circulating in the body
- Radiation therapy, which uses high energy particles to wipe out cancer cells
- Immunotherapy, which uses the body's own immune system to find and destroy cancer cells
- **Targeted Therapy**, which involves using treatments that target specific characteristics of cancer cells to block their growth and spread. Because targeted therapy is directed just at the cancer cells (and has less effect on healthy cells), these treatments tend to have fewer side effects.

A person's plan of care may include one or more of these treatments, as well as others not listed here. As our understanding of cancer improves, new treatments are emerging that help people live longer healthier lives.

> When people tell me that my experience with cancer inspires them, it sometimes dumbfounds me. I think that I got through my experiences by just putting one foot in front of the other and by counting on a lot of support. ~Natalie

## Your Medical Care Team



"We tend to get caught up in statistics and averages, but no two cancers ever behave exactly the same way. Each individual has different genes and an immune system, a distinctive will to live, and an urge to fight. These cannot be measured on charts or graphs."

~ National Cancer Institute

You and your caregivers are important members of the healthcare team. As such, it is important that you participate in your care, ask questions and make sure that you understand and can follow your treatment plan. It is also helpful for you to know the names of roles of members of your care team, so be sure to jot down this information. This will help you know who to reach out to in order to get the help you need.

As part of an academic medical center and teaching hospital, UCSF combines the best in research, clinical care and education to provide advanced treatments that may not be available at other hospital. Our collaborative approach to care means that you will likely be seen by a number of different types of doctors, nurses, and other clinicians, who are often referred to as **providers**.

If your English is not fluent and you prefer to discuss your medical issues in your spoken language, you can request to have a medical interpreter free of charge.

**Doctors, also called Physicians (MD) or Medical Providers** will direct your care. In addition to your main doctor, called an **Attending Physician**, you may receive care from:

- Fellows, who are licensed physicians with specialized training who are furthering their expertise in a sub-specialty
- Residents, who are licensed physicians completing additional specialty training
- Medical Students, who may accompany other providers as part of their education.

There are also physicians and other clinicians at the **UCSF Osher Center for Integrative Medicine** who are trained in therapeutic approaches from around the world, including acupuncture, nutrition, and various stress reduction practices. The Osher Center can be reached at **415-353-7700**.

#### Nurse Practitioners (NP) and Physician Assistants (PA) have

advanced medical degrees and share responsibility with your doctor for your overall treatment plan and care. They will help develop a care plan, conduct physical examinations, order medications and tests, and assist in managing your symptoms or side effects from treatment.



**Registered Nurses (RN)** will tell you what to expect, respond to your phone calls, and will work with your doctors to answer many of your questions.

**Medical Assistant (MA)** help prepare you for your appointment, assist with medical procedures, and are present in the room during sensitive medical exams. If you are having an in-person appointment, they will call you in from the waiting room, take your vital signs and record your medical history and medication list. They can also give you updates on your wait time or bring you a glass or water or blanket to make you feel more comfortable. If you are having a video visit, a Medical Assistant may call you before your visit to ask some intake questions and ensure you are set up for the video visit. **Medical Interpreters** facilitate communication between patients, their caregivers, and members of the care team. All patients whose English is limited and who would prefer

to communicate in their spoken language can request to have a Medical Interpreter at **no cost**. Even if you are bringing a family member or friend who does speak English, it is still good to have a Medical Interpreter at your appointment who understands medical terminology. This way your friend or family member can focus on supporting you or taking notes.

Practice Coordinators (PC)

are the people who answer phones, schedule appointments, communicate with your insurance company, and assist with other administrative tasks.

Social Workers (MSW or LCSW) are trained to help people manage the challenges of living with cancer. They provide emotional support





and can help with health insurance and disability benefits, lodging, transportation, and community resources and programs. You can request to speak to a social worker by asking your provider's office for a referral or by calling **(415) 353-4762** for general information.



Ask for a Medical Interpreter! This service is Free.

## Useful Tips and Information



"Reading autobiographies of others who have dealt with cancer has been really helpful. It is comforting to know that others have gone through similar experiences, sometimes more difficult than mine."

~ Janet

The experience of being diagnosed with cancer and having to navigate the health care system can be very overwhelming. The tips and suggestions on the next few pages will help your visits go more smoothly.

#### **Scheduling Your Appointments**

We offer two types of appointments:

- In-person appointments, where you come in to the medical center to be seen
- Video appointments, which are also called telehealth visits. Telehealth visits allow you to talk to your doctor and be treated from the comfort of your home. Instructions for signing up for video visits are available at videovisit.ucsf.edu.

If your situation is not urgent, and you do not need to be physically examined or undergo a procedure, you may be able to choose a video visit. Please be aware that video visits are billed in the same way as in-person visits, and all the same rules about copays and deductibles apply.

Avoid scheduling time-sensitive activities (such as picking up kids from school or catching an airplane) too close to the time of your scheduled appointment.

#### **Preparing for Your In-Person Appointment**

Please bring the following to your in-person appointments:

- Your insurance information and photo identification (usually a driver's license or ID card)
- A list of questions to ask your doctor
- Information about new symptoms or other health issues
- A list of medications you are taking, including herbal supplements

#### Preparing for Your Video Visit (Telehealth Appointment)

Prepare for your video visit by downloading the free **Zoom Cloud Meetings** App onto your smart phone, tablet, or computer, and then do a test meeting at https://zoom.us/test.



Once you have scheduled your video visit, you will receive an invitation with a Zoom Meeting ID number and a link to join.

Five minutes before your appointment, click on the Zoom link to join the video visit. If this does not work, open Zoom on your device or go to https:// ucsf.zoom.us, Click "Join a Meeting" and type in the Zoom Meeting ID number that you received.

If you need help setting up your video visits, contact MyChart Customer Service at **415-514-6000.** 

#### After Your In-Person or Telehealth Appointment

You can review what was discussed during your appointment by reading the **After Visit Summary** (AVS) or reading the doctor's medical notes in **Notes**. Both your After Visit Summary and the medical Notes can be found in the "Visits" tab next to the day of your appointment. You can also request to have your AVS printed out for you at the end of your in person visit.

If you have any questions or concerns about your medical care, contact your doctor, nurse or the Practice Manager in the clinic where you are seen as they will best be able to resolve the issue. Or, if you feel uncomfortable doing so, you can contact Patient Relations.

## UCSF MyChart: Secure Online Access to Your Health Information



## ucsfhealth.org/mychart 415-514-6000

UCSF MyChart gives you access to your online patient medical record and is an effective way to communicate with members of your care team. You can access it on the web or download the MyChart app onto your phone or other electronic device.

#### **Accessing MyChart**

To sign up for MyChart, you will need an activation code, which you can request at your appointment, find on your after visit summary (AVS) report, or obtain by calling MyChart customer service at **415-514-6000**. You can also log into the MyChart website (ucsfmychart.org) to obtain an activation code.

If you have any trouble signing up, call MyChart customer service at **415-514-6000** or ask the person at the front desk for help.

#### Designating a Proxy – Having a Trusted Person Access Your MyChart Account

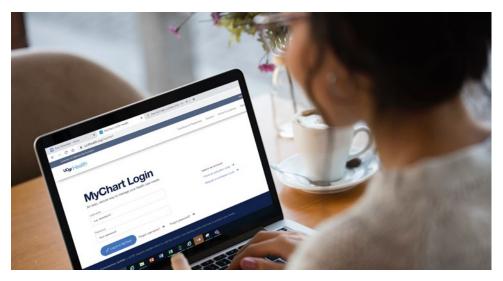
If you have trouble using MyChart or communicating in English, you can allow a trusted friend or family member to log into your MyChart account to view your health information and communicate with your doctors. This process is called "designating a proxy".

To designate a proxy, you will need to:

- Fill out a Proxy Authorization Form, where you will provide the contact information of the friend of family member you have chosen. That person will then receive an email with a link that will allow them to sign-up to your MyChart account.
- You can obtain the Proxy Authorization Form by going to the MyChart website at ucsfhealth.org/mychart, calling the MyChart office at 415-514-6000, or asking the person at the front desk for a copy.

UCSF MyChart allows you to:

- View your health information and test results
- Communicate with your health care team
- View your upcoming appointments
- Refill medications
- Schedule some appointments
- Review and pay bills
- Fill out forms and questionnaires prior to your appointment so that they can be reviewed by your provider before you are seen. (If it is difficult for you to fill out the forms in English, you can arrive early to your appointment and request to have a Medical Interpreter meet with you to help you fill out the forms for your upcoming appointment.)



## Insurance, Billing, and Disability



"Dealing with cancer was like climbing a huge mountain. I thought that the ordeal would be over once I was done with treatment. But, I then realized that I still had to figure out how to climb down the mountain."

~ Michelle

Before starting treatment, we recommend that you contact your insurance plan to verify your health insurance coverage and to find out if your plan covers care at UCSF. You may want to ask whether your plan has a **deductible**, which is a specific amount that you need to pay out of pocket before the rest of the claim is covered. There also may be certain treatments or procedures that your insurance needs to **pre-approve** or **pre-authorize** in order for the cost to be covered. Our office staff will often work with your doctor and insurance company to get the pre-authorizations you need.

If you don't have insurance, or it is not clear whether you have pre-authorization for the visit, we will consider you a self-pay patient and will collect a deposit at the time of your first appointment, regardless of whether it is an in-person appointment or video visit. The deposit amount will be deducted from your total bill.

#### Patient Financial Services Office – Helps Patients after the Appointment

Patient Financial Services can help you **after** your appointment, once you have received your bill. They can help you to:

- Understand your statement balance
- Arrange a payment plan, and
- Get financial assistance (if you qualify), where a portion of your medical bill is forgiven and written off. Those with a family income at or below 400 percent of federal poverty guidelines generally qualify for assistance.



#### Phone: 866-433-4035

You can also communicate with the office through MyChart messaging.

#### Website: ucsfhealth.org/billing-and-insurance

#### Filing for Disability and Leave of Absence - edd.ca.gov/disability

For more information on short-term and long-term disability options, ask to speak to a UCSF social worker. You can also complete your state disability forms online at edd.ca.gov/disability. You may also need to complete forms from your employer. To get information about the forms that your employer requires, contact your employer's Human Resources Department. Once you have filled out your portion of the form, your doctor or nurse will need to complete the medical section.

If you are experiencing financial difficulties with transportation costs, lodging, or other expenses, you can also let a member of your care team know or ask to speak with a social worker.

## Making the Most of Your Visit



"Jwas getting really anxious and depressed that I would have to put off my travel plans to see my family on the East Coast, but when I brought it up with my doctor, she tweaked my treatment schedule so that I could still enjoy my long awaited plans!"

~ Jason

Taking time to prepare for your visit will help you use your time with your doctor more effectively. Make sure to share your concerns and ask questions if you don't understand what is being said.

It is your doctor's role to explain your treatment options, describe advantages and disadvantages of each option, and respond to your questions and concerns.

# Consider having a family member or friend be present (either remotely or in-person)

It is often helpful to have the support of a trusted friend or relative, who can be there with you at your doctor's appointment to listen to what is said, ask questions, and take notes. This person can either be with you at the appointment or participate on the phone or through a video call. You can also contact the Patient Support Corps at **415-476-6004** to request the support of a student intern who can take notes and share them with you.

••••• It is not easy to remember it all!

#### Bring a list of questions

Your doctor and care team are available to help you with any of your questions. Think about the questions you want to have answered and write them down, listing the most important ones first. This way you don't have to try to remember all of them. You can also give the doctor a copy of your questions either at the appointment or send them in beforehand. Let your doctor know about any symptoms you are experiencing and how they are impacting your life.

# If you would like some help preparing for your appointment (including video visits)...

The **Patient Support Corps Program** has student interns (usually pre-medical students) who can help you:

- Make a list of your most important questions and concerns.
- Make an audio recording of your visit with your doctor. (Please make sure to get permission from those being recorded.)
- Take notes and summarize the meeting.



Photo provided courtesy of Susan Merrell, UCSF Public Affairs

Phone: 415-476-6004 Email: psc@ucsf.edu Website: psc.ucsf.edu

#### Take good notes

Take notes during the appointment or obtain permission to make a voice recording of your visit. You can also ask a friend or relative to take notes for you or contact the Patient Support Corps to do so.

#### Keep track of who is on your care team

It is helpful to make a list of all the doctors and health care providers you are seeing, noting their specialty and why you are seeing them. This is also a good list to share with your doctor, particularly if you are seeing health care practitioners at different facilities. There are some blank sheets at the end this guidebook that you can use for this purpose.

#### Share important information with your care team, including:

- Any health problems and symptoms you are experiencing
- Your goals for treatment or any religious or cultural beliefs that may influence your decisions
- Important plans that may need to be coordinated with your treatment, such as a family vacation, a desire to finish a college degree, a wish to start a family, etc.
- Any issue that might make it difficult for you to follow the treatment plan, such as difficulty getting to appointments, paying for parking, taking your medications correctly, or other issues
- The name of the person you choose to make decisions for you in case there is a time when you are unable to make your wishes known. (This can also be documented in a form called an advance directive.)

Don't be afraid to ask questions!

## Calendar of Symptoms

Date	Symptom/Event/Description
November 17	Started chemo: carboplatin
	Light nausea - level 2
Nov. 18	Spoke to nurse Jan and
	started Zofran for nausea –
	feel no navsea, some fatige,
	need afternoon nap.
Nov. 21	Problem with constipation. Spoke to nurse Jan
	Increase fluids and fiber
	Start stool softener – Miralax
	(1 packet daily, as needed).

#### Keep track of your symptoms and care plan

Keeping track of changes in your symptoms, treatment plan, and medications can be very helpful. Make sure to document this information in a place that is easy to access, such as a notebook, a smart phone, or in the blank pages at the end of this guidebook. This will make it easier to track the information and share it with your doctor and care team. Above is an example that shows an effective way to track symptoms and changes.

#### Rest assured that the information you give us is confidential

We are committed to the safety and health of our patients and make it a priority to keep your health and personal information confidential. We do not collect or share information about immigration or citizenship status. And we never release patient information without authorization from the patient, unless we are legally compelled to do so by law.

# Things to Know Before You Go



Before you leave, we recommend that you to ask about:

- The name of your diagnosis
- Your treatment plan and next steps
- The time and place of your follow-up appointments
- The name and roles of different members of your care team
- Who to contact between office visits and how to contact them if you have questions. MyChart (see information below) is an effective way to communicate with your care providers between office visits.

There are some blank pages at the end of this guide for you to keep track of this information.

Name of the diagnosis:	Breast Cancer
Stage of diagnosis:	Stage 2
(if known/relevant)	
Names of your doctor(s):	Dr. Hope Rugo
	Ŭ



## UCSF Cancer Programs and Services



## cancer.ucsf.edu/support

"(Jf I feel my emotions, I'll move through them. If I fear my emotions and thoughts, then the one constant I will live with is fear..."

#### ~ Lauren

All programs and services are offered free of charge, unless stated otherwise. Interpreting services are available for some programs. Please note that many of the support groups and other programs are offered online, providing you with the option of participating from the comfort of your home.

More information about each of the programs is available at cancer.ucsf.edu/support.

• • • • • • • • • • • • • •

### Art for Recovery

The Open Art Studio provides workshops for patients and their caregivers to express themselves through drawing, collage, poetry, writing and music. You don't need to have any art experience to participate in this supportive and welcoming program.

I know actual happiness when immersed in art. ~Greg

Phone: 415-885-7225

#### **Cancer Clinical Trials**

A clinical trial is a research study used to test new medical approaches to detecting, preventing, diagnosing and treating diseases. It is through clinical trials that researchers determine whether new treatments are safe and work better than current treatments. Each study has its own rules about who can participate. Some clinical trials, for example, may require individuals to be within a certain age range or have a particular type of cancer. UCSF offers many clinical trials to study new cancer treatments.

#### Phone: 877-827-3222

#### **Cancer Genetics and Prevention Program**

If you have had cancer before, or cancer runs in your family, a licensed genetic counselor can review your personal and family medical history and provide information to you and members of your family about cancer risk, cancer screening, and prevention measures. They may also recommend additional genetic testing. Services are available for a fee. Most insurance companies cover these services.

#### Phone: 415-885-7779

The artwork used in this guidebook was created by patients, families, caregivers, and medical staff in Art for Recovery, a program at the UCSF Helen Diller Family Comprehensive Cancer Center.

### **Clinical Cancer Genomics Laboratory (CCGL)**

UCSF's **Clinical Cancer Genomics Laboratory (CCGL)** is one of the few facilities in the country that uses the UCSF500 Gene Panel test to identify genetic changes (called mutations) in the DNA of a patient's cancer cells. This test can help identify the exact type of cancer a patient has and can indicate potential targeted treatments to slow or eliminate the cancer. To unders-



tand whether the UCSF5000 Gene Panel test could be an appropriate next step in your cancer treatment, talk to your doctor or read more about it online.

#### **Communicating with Your Doctor and Care Team**

The **Patient Support Corps** trains students (usually premedical students) to help patients prepare for their medical appointments and communicate with their care team. They can help you prepare for your medical appointments by:

- Sending you information about your condition
- Working with you to put together a list of questions for your doctor
- Participating in your visit (in-person or by phone) to take notes about what is said
- Showing you how to make an audio-recording of your visit. (You will need to ask your medical provider for permission.)

Phone: 415-476-6004 Email: psc@ucsf.edu

# **COMPASS:** Acting Mindfully for a Valued Life for Cancer Patients and Survivors

This seven-week series, which is open to UCSF cancer patients, focuses on teaching mindfulness, distancing from difficult thoughts, and acceptance of challenging emotions as a way to manage emotional distress, symptoms, and side effects. Based on Acceptance and Commitment Therapy (ACT), the program helps patients identify personal values that can serve as guiding principles in leading meaningful lives. Services are available for a fee. Most insurance companies cover these services. Call the Psycho-Oncology Service for more information or to register.

#### Phone: 415-353-7019



••••• *Links to all these programs can be found at* cancer.ucsf.edu/support

### **Everything You Need to Know About Our Programs and Services**

This guidebook, which you are currently reading, has been written with help and input from the Patient and Family Advisory Council and is designed to give you an overview of programs and services available to patients treated for cancer at UCSF. We hope you will use this information to help navigate your care and access the support and services you need.

You can also view an online presentation to get an overview of the programs and services offered at UCSF. The presentation is available in several languages including Spanish (Español), Cantonese (**廣東話**), Mandarin (普通話), and others.

### **Exercise and Movement Classes**

Exercise can help you improve your strength, reduce fatigue, and improve your mood. Our exercise classes, which are specifically designed for people with cancer, include Core & More strengthening exercises and also yoga. A completed waiver and health history form is required. The waiver is available on the website or at your first class.

For Yoga, call the Osher Center for Integrative Medicine at 415-353-7718



For Core and More (Pilates strengthening exercises), call 415-514-6430

### **Exercise Counseling**

If you are receiving your cancer care at UCSF, you may also make a free one-hour appointment with a professional trainer to design an exercise program tailored to your needs.

Phone: 415-502-5547

### **Fertility Preservation Program**

If you are concerned about your fertility and would like to know more about your options to have children now or in the future, the Fertility Preservation Program can assess your situation, educate you about your options, and provide fertility preservation services, such as freezing of eggs, sperm or embryos. The services will be coordinated with your cancer care. Many insurance companies will cover these services.



#### Phone: 415-353-9115

### Friend to Friend Specialty Shop

This boutique store offers many cancerrelated products, including wigs, hats, breast prostheses, mastectomy bras, scarves and other items. The services also include a free wig trim, which you can get by calling to schedule an appointment in advance. The store has two locations – one at Mission Bay (1825 4th Street) and the other at Mount Zion (1600 Divisadero Street).



### Phone: 415-353-7776

### **Knitting**

Relax and talk with others as you create knitted hats, scarves and other woolly items. New and experienced knitters welcome. Yarn, needles and instruction are provided. This program is located at the Mount Zion campus and takes place on Thursdays from 12:00 – 1:00 pm at 1600 Divisadero Street, Room B101. Please call to verify time and location.

#### Phone: 415-885-3693



### Lodging

The UCSF **Short Term Lodging Guide** lists hotels in the area. You also may be eligible to stay at the Koz Hospitality House, which primarily servers our cancer patients. It is available at \$125 a night or on a sliding scale. To get assistance from a social worker to find or pay for lodging, ask a member of your care team for a referral.

Social Work Phone: 415-353-4762 Lodging Website: https://tiny.ucsf.edu/STLG

### **Meditation and Guided Imagery**

The Patient and Family Cancer Support Center offers weekly meditation and guided imagery sessions for people living with and recovering from cancer. All levels of experience welcome!

Phone: 415-885-3693

**Meditation Rooms** are available at the following locations:

 The Mission Bay Meditation Room is in C1401 at 1975 4th Street, near the Children's Hospital lobby. There is also an adjacent meditation garden and labyrinth.



- The Parnassus Meditation Room is in M193 at Moffitt/Long Hospital, 505 Parnassus Ave, next to the information desk, as well as at several other locations.
- The Mount. Zion Meditation Room is in the main lobby of the Cancer Center at 1600 Divisadero Street.

### **Nutrition Counseling and Workshops**

Our dietitians, who specialize in cancer care, hold free workshops and classes about diet and cancer They also meet individually with patients receiving cancer care at UCSF to provide advice on healthy eating during and after cancer treatment. To schedule a free appointment, contact your oncologist's office for a referral.

Nutrition Counseling: 415-502-5547 Nutrition Workshops: 415-885-3693



### **Osher Center for Integrative Medicine**

The practitioners at the Osher Center integrate modern medicine, healthy lifestyle practices, and healing approaches from around the world. Programs promote healing and well-being of the whole person - mind, body and spirit. Services are available for a fee. Some insurance companies may cover these services.

Phone: 415-353-7700 Website: osher.ucsf.edu

### **Patient and Family Cancer Support Center**

The Patient and Family Cancer Support Center supports wellness and healing by providing patients and their loved ones with information, emotional support, community resources, and a listing of cancer-related events both within and outside of UCSF. You are invited to call the center, and, once COVID19 restrictions are lifted, visit our centers at our Mission Bay and Mount Zion. If you would like to be added to our monthly



e-Newsletter and to receive our Calendar of Events, please click here or call us at **415-885-3693**.

You can also call us to find out about ways to join and participate in our many cancer support programs. For a full listing of our programs, go to <a href="https://cancer.ucsf.edu/support">https://cancer.ucsf.edu/support</a>

Phone: 415-885-3693 Email: CancerSupportCenter@ucsf.edu

### **Patient Relations**

If you have questions or concerns about your cancer care, it is recommended that you first discuss your concerns with your doctor, nurse, practice manager, or social worker. If your concerns remain unresolved, the staff at Patient Relations is available to help you.

Phone: 415-353-1936 Email: patient.relations@ucsf.org Website: ucsfhealth.org/services/patient-relations



### **Peer Support Program**

The Peer Support Program staff can put you in touch with someone who has had the same cancer diagnosis as you. They can also connect you to a person who has undergone the same treatment or who has a similar life situation, such as being a young parent with cancer. You can contact the program if you would like to speak to a peer volunteer by phone or if you would like to become a peer volunteer.



#### Phone: 415-885-3693

### **Psycho-Oncology Services**

Cancer patients can speak with a psychologist to help cope with their diagnosis and difficult emotions. They can also see a psychiatrist who can prescribe medications to help cope with depression or anxiety. Ask your UCSF oncologist's office for a referral or call directly. Services are available for a fee, which may be covered by insurance.

Phone: 415-353-7019

### **Social Work**

Social workers are trained to help people manage the challenges of living with cancer. They provide emotional support and short-term counseling, and can provide information about **insurance and disability** benefits and **community resources.** You can also reach out to them if you are having difficulty with traveling to and from your appointments or need help with hotels and lodging. They can also help you with **Advance Care Planning**, which involves documenting your wishes for care, including naming a person whom you'd like to make decisions for you if you cannot speak for yourself. Social workers are available to all UCSF patients receiving cancer care. To speak with a social worker, ask a member of your care team for a referral.

#### Phone: 415-353-4762



• • • • Links to all these programs can be found at cancer.ucsf.edu/support

### **Spiritual Care**

Chaplains at UCSF provide emotional and spiritual support and comfort, and can facilitate religious rituals for individuals or groups. Spiritual Care staff also facilitate grief support groups for those who have experienced the loss of a loved one.

Mission Bay Phone: 415-514-4200 Parnassus and Mount Zion Phone: 415-353-1941

### **Stop Smoking Programs**

Quit smoking, or prevent smoking relapse, with help from the UCSF Fontana Tobacco Treatment Center. Group classes are available for a fee.

Phone: 415-885-7895

### **Support Groups**

Receive support and information by speaking with others. UCSF offers approximately 15 support groups for cancer patients and loved ones. The Patient and Family Cancer Support Center can also refer you to other groups throughout the Bay Area, including groups offered in Spanish, Cantonese and Mandarin.

### Phone: 415-885-3693



### Survivorship Wellness Group Program (Post Treatment)

Survivorship Wellness is an 8-week program to help UCSF patients who have completed their cancer treatment. Participants will learn about nutrition; physical activity; managing stress; sleeping well; and sexual, emotional, and spiritual wellness. Registration and screening is required prior to program participation. To register, call or visit the website.

### Phone: 415-353-3931

### Symptom Management Service (SMS)

The Symptom Management Service (SMS) offers palliative care to patients at any stage of their cancer treatment. **Palliative care** is treatment that focuses on improving quality of life by treating all aspects cancer - the physical, emotional, and spiritual. This includes treating pain, fatigue, depression, anxiety, or helping with advance care planning. The SMS staff also offer home visits to UCSF patients living in San Francisco who are homebound



with serious illness. These visits will take place within the possibilities allowed by COVID safety concerns. In order to meet with a member of the SMS team, you will need to get a referral from a member of your health care team. Services are almost always covered by health insurance.

Phone: 415-885-7671 Website: cancer.ucsf.edu/sms

### Workshops, Events, and Retreats

Subscribe to the Patient and Family Cancer Support Center newsletter to find out about upcoming cancer programs, educational seminars, retreats, and workshops. You can view the most recent copy of the newsletter by going to the main cancer support site cancer.ucsf.edu/support and clicking on the "Latest Support Newsletter" tab. To sign up to receive a copy of the monthly newsletter via email click here or calling the Cancer Support Center.

### Phone: 415-885-3693

••••• *Links to all these programs can be found at* cancer.ucsf.edu/support

### Living Now, Planning for the Future



We all come into this world with an uknown expiration date. Knowing that I am mortal, that we are all mortal, reminds me to appreciate each day and do that which makes me come alive and brings joy.

~ Kerim

### What is Advance Care Planning?

Advance care planning involves talking to your doctors and the people who matter most in your life about the type of treatment you would like to have in the event that you are unable to state your wishes or make medical decisions about your treatment.

Knowing what is important to you and the type of care you would want can help you plan now so that your wishes for care and treatment are honored in the future.

Advance care planning is for everyone. Something unexpected can happen at any age. As long as you can communicate and make medical decisions, your stated wishes will be honored - regardless of what you have said in the past or written in your Advance Directive.

A convenient way to begin this discussion is to bring it up at one of your medical appointments. This way, your wishes will be documented in your medical record and your medical providers will know what is important to you and the type of care you want to receive in an emergency situation or in the event you can no longer participate in medical decision-making. You can also document your medical wishes in a form called an **advance directive**.

### What is an Advance Directive?

An advance directive is a form where you write down your wishes for medical care. An advance directive allows you to:

- Name a trusted person to help make medical decisions for you if you are unable to do so.
- Let your caregivers and doctors know what kind of treatments and care you may want in different situations.

### Why Is It Useful to Have an Advance Directive?

- An advance directive can reduce stress for family and caregivers because they don't have to "guess" what type of care the patient wants.
- Patients feel more secure in knowing that their wishes for treatment and care will be respected.
- Advance directives can provide specific instructions that are important to the patient. Examples include:
  - "I do not want my sister to make decisions on my behalf."
  - "If my care team says that my condition is incurable and I have a short time to live, I do not want to be put on a ventilator."
  - "Pain control is my priority. I do not want to suffer."

### Where can I get an Advance Directive?

Advance directives can be obtained:

- At your clinic visit or the front desk when you check-in for your appointment.
- Online there are many different formats available for you to choose from. The two forms that many of our patients use include the easy-to-read PREPARE form (prepareforyourcare. org), which is described below and the advance directive developed at UCSF, which will download directly upon clicking this link (ucsfhealth. org/pdf/advance\_health\_care\_directive.pdf).

### PREPARE - prepareforyourcare.org

- The PREPARE website offers:
- A step-by step program with video stories.
- Tips for talking with your family, friends, and medical providers about your wishes.
- Free advance directives in **Spanish**, **Chinese**, **Russian** and other languages (https:// prepareforyourcare.org/advance-directive).

### How Can I Get Help?

If you would like some help in thinking through your options or filling out an advance directive, contact your social worker or talk to a member of the Symptom Management Service team. You can also get this information by attending the free monthly workshop described below.



*Remember, you can change and update your advance directive at any time.* 

An advance directive reduces confusion in the case of an emergency by letting your doctors and caregivers know who should make decisions for you and what type of care you want and don't want.

### Monthly Advance Care Planning Workshop - What Matters Most?

The MERI Center offers free monthly workshops called **What Matters Most?** In the workshops, you can meet with an experienced staff person in a supportive group setting to think through your preferences for future care. This workshop is offered online and in-person and is for everyone – patients and their caregivers, old and young, and healthy and sick. It is designed to help you write down your wishes in a document called an **advance directive**. To sign up for the "What Matters Most Workshop" or to find out about other program offerings, contact the MERI Center.

Phone: 415-509-8645 Website: meri.ucsf.edu

### What Do I Do with an Advance Directive Form?

Once you fill out an advance directive, you will need to have it signed by either two friends or family members or by a Notary Public. Notary services are available at many

businesses, including photocopy shops, parcel shipping stores (such as UPS), libraries, etc.

Once your advance directive is signed, make sure to give one copy to your doctor and copies to family members or friends involved in your care. You can also scan a copy and send it to your doctor via My Chart).



### Care in Life's Last Chapter (End of Life Care)



"I've found that sitting with my feelings, not running away from them, has helped me resolve my sadness and anger."

~ Dan

### POLST FORM- Physician's Order for Life Sustaining Treatment - https://capolst.org/

A POLST form is a physician's order that lets emergency personnel who respond to an emergency call know about a patient's preferences for care. Although the emergency personnel may not have access to the advance directive, they are trained to look for a POLST form, which can be worn as a bracelet or displayed in a visible place, such as on the refrigerator. They will follow the instructions on the POLST form when providing emergency care.

Patients with advanced or serious illness can get a POLST form from their physician.



Translations of the POLST form are available at https://capolst.org/. However, translated versions of this form are for reference only; an English version of the POLST form must be completed and signed so that emergency medical personnel and healthcare providers can follow the orders.

### Hospice

Hospice care refers to care provided by a team of providers that focuses on reducing suffering, providing comfort, and improving quality of life. Hospice care is available for individuals who are expected to live for about six months or less. However, some patients in hospice live longer, or, in some cases, recover.

You can request information about hospice from a social worker, Symptom Management Service, or any one of your providers. Hospice care is covered by Medicare and most insurance companies.

There are a few hospice facilities that specialize in providing around-the-clock comfort care. But most hospice services are



provided in the home of the patient, with nurses and other care providers visiting a few times a week to help with bathing, pain management, and care to help patients feel more comfortable. The rest of the care is generally provided by family members, friends, or paid caregivers.

### Hospice care provides:

- Drugs and treatment to provide relief from pain and symptoms
- Emotional and spiritual support to the patient and family
- Care at home or at a hospice facility
- Medical equipment and supplies
- Education to the family about how to care for the patient

## What Are We Doing Well? How Can We Do Better



### Do You Have Ideas to Improve the Patient Experience?

Help us help you. Please let us know how we can better serve you by sharing your feedback and experiences on our website ucsfhealth.org/CC-ImprovementIdeas.

### Do You Have Concerns about Your Care?

If you have concerns about the medical care you are receiving or have received, please discuss your issue with your doctor or nurse. If you do not feel comfortable doing so, you can get in touch with the **Practice Manager**. This is the person in charge of the day-to-day operations of the clinic where you are being seen. If your concerns remain unresolved, you can contact **Patient Relations** at **415.353.1936** or **patient.relations@ucsfmedctr.org**.

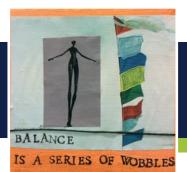
### Do You Have Comments about this Guidebook?

If you have comments about this guidebook or would like to provide feedback, please do so by sending an email to guidebookfeedback@ucsf.edu.



### Thank Someone Who Works at UCSF

If you would like to recognize and thank a staff member who has provided exceptional service or care, please go to ucsfhealth.org/thank-an-employee-or-physician.



### Finding Your Way Around UCSF

"Although we don't always control what happens to us, we can have some say over how we respond and relate to our experiences."

~ Oren

We offer cancer care at several campuses in San Francisco and around the greater Bay Area. Depending on the type of cancer you have and the treatment you are getting, you may be seen at different locations. The following section covers information about traveling to our various centers.

### Main San Francisco locations pathway.ucsfmedicalcenter.org

- Mission Bay, 1825 4th Street, San Francisco, CA 94158
- Parnassus Heights, 400 Parnassus Avenue, San Francisco, CA 94117
- Mount Zion, 1600 Divisadero Street, San Francisco, CA 94115
- China Basin, 185 Berry Street, San Francisco, CA 94107

### Bay Area Satellite Locations Offering Cancer Care:

### **UCSF Cancer Center Greenbrae**

1100 S. Eliseo Dr, Suite 1 Greenbrae, CA 94904

Phone: 415-502-4334 Fax: 415-885-7662 ucsfhealth.org/cancer-greenbrae

### UCSF-John Muir Health Cancer Center Berkeley

Berkeley Outpatient Center 3100 San Pablo Avenue, Suite 430 Berkeley, CA 94702

Phone: 510-420-8000 Fax: 510-420-8001 ucsfhealth.org/cancer-berkeley

### **UCSF Cancer Center San Mateo**

Crystal Springs Shopping Village 218 De Anza Blvd. San Mateo, CA 94402

Phone: 650-341-9131 Fax: 650-341-9135 ucsfhealth.org/cancer-san-mateo

### **UCSF** Cancer Services

#### SAN FRANCISCO

UCSF Health at Mission Bay Bakar Precision Cancer Medicine Building 1825 4th St. | 94158

UCSF Health at Parnassus Medical Building 1 400 Parnassus Ave. San Francisco, CA 94143

UCSF Health at Mount Zion Helen Diller Family Comprehensive Cancer Center 1600 Divisadero St. | 94115

#### BERKELEY

UCSF-John Muir Health Cancer Center Berkeley Outpatient Center 3100 San Pablo Ave., Suite 430 94702

### SAN MATEO

UCSF Cancer Center San Mateo Crystal Springs Village 218 De Anza Blvd. | 94402

### GREENBRAE

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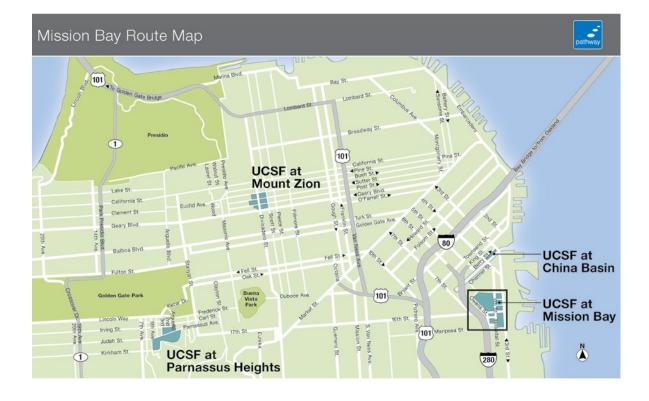
UCSF Gynecologic Oncology 1100 S. Eliseo Dr., Suite 1 | 94904





### Traveling to Our San Francisco Locations

### Transportation.ucsf.edu



### **Driving by Car**

Information about getting to UCSF can be found at pathway.ucsfmedicalcenter.org or by calling:

- Mission Bay: 415-476-1511
- Mount Zion: 415-514-8935
- Parnassus: 415-476-2566

Managing traffic and parking can take time, so please take this into consideration.

# Parking Information – park.ucsf.edu/

- Mission Bay and Parnassus: Hourly parking is available for \$5.25/hour, with a maximum daily rate of \$35. Patients with a disabled placard pay a daily parking rate of \$7.
- Mount Zion: Hourly parking is available for \$7/hour, with

a maximum daily rate of \$35. Patients with a **disabled placard** pay a daily parking rate of \$12.

To check for open parking spaces in the garages, go to https://park.ucsf.edu/ or down load the UCSF Mobile app, click the "Go" tab, and click "MB Parking Availability."

### Valet Parking

Valet services will park your car at no charge, but you will need to pay regular parking fees charged by the garage. Valet services for our main campuses are located at:

- Mission Bay 1825 4th Street, San Francisco, CA 94158
- Parnassus Heights 400 Parnassus Avenue, San Francisco, CA 94117
- Mount Zion 1600 Divisadero Street, San Francisco, CA 94115



## **UCSF** Shuttle

### Phone: 415-476-4646 (GOGO) Website: Shuttles.ucsf.edu

# •• The UCSF shuttle service is free to UCSF patients and their visitors and travels between the UCSF campuses and transit centers.

- The **Red Line** shuttle connects the Mission Bay campus to the 16th Street BART station
- The Line Line shuttle connects Parnassus to the 16th Street BART station.
- The Blue and Gold Line shuttle connects the Mount Zion campus to Civic Center BART station.

If the driver asks for identification, you will need to identify yourself as a patient or a visitor of a patient. All UCSF shuttles are equipped with wheelchair lifts for people with mobility challenges.

You can check real-time shuttle departures at LiveShuttle.ucsf.edu, which is also accessible on your mobile phone, via the UCSF mobile app. In addition to shuttle schedules there is a trip planner to help you plan your trip.

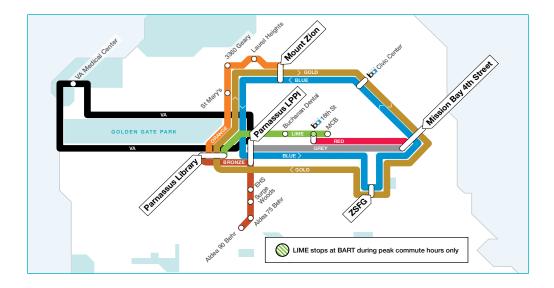
### **Public Transportation**

There are many other ways to get to UCSF locations, including

- Muni / San Francisco Municipal Railway – SFMTA.com or 415-673-6864 (MUNI)
- Caltrain http://www.caltrain. com/schedules.html
  - Connects to Mission Bay via the green shuttle line or the KT Muni line.
  - Connects to Parnassus via N-Judah Muni line.
- San Francisco Bay Ferry sanfranciscobayferry.com or 1-877-643-3779, connects to Mission Bay via the KT Muni line.

# **UCSF Shuttle Map**







Tap into *live* real-time departures, schedules, and trip planning. Scan or Visit: **shuttles.ucsf.edu** 



For a schedule of shuttle times, go to shuttles.ucsf.edu

### Tracking Your Care —

### Calendar of Symptoms and Healthcare Events

Use these pages to record your important medical information.

Date	Symptom/Event/Description

Tracking Your Care -

# Things to Know Before You Go

 What is my diagnosis?	
TreatmentPlan/Next Steps	
 •	
•	
 •	
 Date and Location of follow up appointment:	
Who did I see for my care today?	
59	



This guidebook is available in English, Espaniol (Spanish), and 中文(Chinese)

Copies of the guidebook can be requested at the front desk or by calling the Patient and Family Cancer Support Center 415-885-3693.

They are also available online at cancer. ucsf.edu/guidebook.

> November 2021 Made accessible 4/23