Navigating the UCSF Helen Diller Family Comprehensive Cancer Center
Navigating the UCSF Helen Diller Family Comprehensive Cancer Center: 

Information, Support, and Resources

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

A special thanks goes to members of the Patient and Family Advisory Council for their contribution.
Thank 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 Ashworth, PhD, FRS
President, UCSF Helen Diller Family Comprehensive Cancer Center

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.
You Are Not Alone.

There are many people and services here to help you navigate your cancer journey.
Cancer 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.
# Important UCSF Phone Numbers and Websites

## UCSF Operator- 415-476-1000
(Directs you to UCSF staff, UCSF departments, and to patients in the hospital.)

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<th>Program</th>
<th>Telephone</th>
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<tr>
<td>Art for Recovery</td>
<td>415-885-7221</td>
<td>cancer.ucsf.edu/support/afr</td>
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<tr>
<td>Cancer Genetics and Prevention Program</td>
<td>415-885-7779</td>
<td>ucsfhealth.org/education/cancer_genetics_and_prevention_program</td>
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<td>Clinical Trials</td>
<td>877-827-3222</td>
<td>cancer.ucsf.edu/clinical-trials</td>
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<td>Exercise Classes</td>
<td>415-885-3693</td>
<td>cancer.ucsf.edu/exercise-classes</td>
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<tr>
<td>Exercise Consultation</td>
<td>415-514-6430</td>
<td>ucsfhealth.org/services/cancer_exercise_counseling</td>
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<tr>
<td>Fertility Preservation Program</td>
<td>415-353-9115</td>
<td>crh.ucsf.edu/fertility-preservation</td>
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<tr>
<td>Financial Services</td>
<td>866-433-4035</td>
<td>ucsfhealth.org/billing_and_records</td>
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<tr>
<td>(understanding medical bills, arranging payment plans, or requesting financial assistance)</td>
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<tr>
<td>Friend to Friend Specialty Shop</td>
<td>415-353-7776</td>
<td>friend2friend.org</td>
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<td>Health Information for Patients and Families (Fishbon Library)</td>
<td>415-885-7285</td>
<td>tiny.ucsf.edu/medicalquestions</td>
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<td>Imaging Library/Film Library (to obtain CDs with images from Radiology)</td>
<td>415-353-1640</td>
<td>ucsfhealth.org/billing_and_records/medical_records/</td>
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<td>Infusion Center</td>
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<td>Mount Zion</td>
<td>415-353-7155</td>
<td>ucsfhealth.org/clinics/ida_friend_infusion_center</td>
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<td>Mission Bay</td>
<td>415-353-7155</td>
<td>ucsfhealth.org/clinics/infusion_center_at_mission_bay</td>
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<td>Parnassus</td>
<td>415-353-2272</td>
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<td>Interpreting Services</td>
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<td>Call the Practice providing your care</td>
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<td>Providing your care</td>
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<td>ucsfhealth.org/services/interpreters</td>
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<td>Legacy Project</td>
<td></td>
<td>ucsflegacyproject.com</td>
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<tr>
<td>Lodging Resources Short-Term</td>
<td></td>
<td>campuslifeservices.ucsf.edu/housing/services/short_term_lodging_needs</td>
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<tr>
<td>Lymphedema Management and Risk Reduction</td>
<td>415-353-7908</td>
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<tr>
<td>Medical Records (to obtain copies of your records)</td>
<td>415-353-2221</td>
<td>ucsfhealth.org/billing_and_records/medical_records/</td>
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<td>Meditation and Guided Imagery</td>
<td>415-885-3693</td>
<td>cancer.ucsf.edu/meditation-and-guided-imagery</td>
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<tr>
<td>MyChart</td>
<td>415-514-6000</td>
<td>ucsfhealth.org/ucsfmychart</td>
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<tr>
<td>New Patient and Caregiver Online Orientation</td>
<td>415-885-3693</td>
<td>cancer.ucsf.edu/orientation</td>
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<td>Nutrition Consultation</td>
<td>415-502-5547</td>
<td>cancer.ucsf.edu/nutrition-counseling-and-workshops</td>
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<td>Nutrition Seminars and Events</td>
<td>415-885-3693</td>
<td>cancer.ucsf.edu/nutrition-counseling-and-workshops</td>
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<td>Osher Center for Integrative Medicine</td>
<td>415-353-7700</td>
<td>osher.ucsf.edu</td>
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<tr>
<td>Patient and Family Cancer Support Center</td>
<td>415-885-3693</td>
<td>cancer.ucsf.edu/csc</td>
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<td>Patient Relations Office</td>
<td>415-353-1936</td>
<td>ucsfhealth.org/services/patient_relations</td>
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<td>Patient Support Corps</td>
<td>415-476-6004</td>
<td>psc.ucsf.edu</td>
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<td>Peer Support Program</td>
<td>415-885-7210</td>
<td>cancer.ucsf.edu/peer-support</td>
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<tr>
<td>Psycho-Oncology Team</td>
<td>415-353-7019</td>
<td>cancer.ucsf.edu/support/psycho-oncology</td>
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<td>Radiation Oncology (radiation treatment)</td>
<td>415-353-7175</td>
<td>radonc.ucsf.edu</td>
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<tr>
<td>Radiology (imaging, scans)</td>
<td>415-353-3900</td>
<td>radiology.ucsf.edu</td>
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<td>Security</td>
<td>415-885-7890</td>
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<td>Smoking Cessation</td>
<td>415-885-7895</td>
<td>ucsfhealth.org/tobaccotherapy</td>
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<td>Social Work</td>
<td>415-885-3693</td>
<td>ucsfhealth.org/services/oncology_social_work</td>
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<td>Spiritual Care Services</td>
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<td>ucsfspiritcare.org</td>
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<tr>
<td>Support Groups</td>
<td>415-885-3693</td>
<td>cancer.ucsf.edu/support-groups</td>
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<tr>
<td>Surgery Wellness Program</td>
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<td>geriatric.surgery.ucsf.edu/wellness-program</td>
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<td>Survivorship Wellness Program</td>
<td>415-353-3931</td>
<td>ucsf.edu/support/survivorship-wellness</td>
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<tr>
<td>Symptom Management Service</td>
<td>415-885-7671</td>
<td>cancer.ucsf.edu/support/sms</td>
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<td>Thank and Recognize Exceptional Staff</td>
<td></td>
<td>ucsfhealth.org/thank_an_employee</td>
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<td>Transportation Parking and Directions</td>
<td>415-476-1511</td>
<td>campuslifeservices.ucsf.edu/transportation</td>
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<tr>
<td>UCSF Shuttle Service</td>
<td>415-476-4646 (GOGO)</td>
<td>LiveShuttle.ucsf.edu (real time departures)</td>
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| Wheelchair Escort               | Mount Zion 415-885-7255  
Parnassus 415-353-1664  
Mission Bay 415-476-1540 |                                                  |

### Tips and Information

"Perhaps this is what 'surviving' is: the will to go forward and make of something harsh and destructive, something generous and life-giving. There are things that are universal; loss and hope and moving on."

- Desiree

Welcome to the UCSF Helen Diller Family Comprehensive Cancer Center. The suggestions below will help your visits go more smoothly.

**UCSF MyChart - ucsfmychart.org**

Signing up for MyChart will facilitate your care at UCSF – making it easier for you to access your health information, communicate with your health care team, refill medications, and much more.

To sign up for MyChart, you will need an activation code, which you can pick up at your appointment, find on your visit summary 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.
MyChart (ucsfmychart.org) will allow you to:

- Communicate directly with your health care team
- View your upcoming appointments
- Update your medications and allergies
- Refill medications
- View test results
- View your health information on your smartphone or mobile device using the MyChart app
- Allow another adult to log in to your MyChart account to view your health information and communicate with your doctors. This is called “designating a proxy”.
- Complete required forms prior your appointment so that they can be reviewed by your provider before you are seen. Doing so will allow you to use your appointment time more effectively, preventing delays for you and other patients.

Scheduling Your Appointments

- If your English is limited, please ask for a Medical Interpreter when scheduling your appointment.
- If you are hard of hearing, or are deaf, you can request to have a sign language interpreter scheduled for the time of your visit.
- 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.

On the Day of Your Appointment

- Bring the following:
  - Your insurance information and photo identification
  - 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
- Arrive on time! Keep in mind that your expected arrival time may be earlier than your appointment time. Remember to allow time for transportation and parking, as these can sometimes take longer than expected.
- If you know you will be arriving late, call the Practice to let them know when to expect you.
- If your appointment is delayed, check in with the staff to see if there is time for you to walk around, get food or visit the Patient and Family Cancer Support Center.
- If you are handed a Real-Time Locating System (RTLS) badge at registration, please wear it with the button facing out and do not place it in your pocket or purse or cover it with a jacket. The Cancer Center uses these badges to facilitate patient care and communication, and to reduce delays and wait times.

After your Appointment

- Once you have completed all of your appointments for the day, please remember to drop off your RTLS badge in an RTLS drop box. It is important that you do not take your badge home with you. However, if you do, your badge can be returned by dropping it in any blue USPS mailbox—no envelope or postage required.
- Read your After Visit Summary (AVS) to review follow-up instructions from your visit. A copy of your AVS will be handed to you at check-out, and you can also review it on MyChart.
- Contact the Practice where you are seen if you have any questions or concerns about your medical care.
Before your first appointment, we recommend that you contact your insurance plan to verify your coverage and benefits and to confirm that your plan will cover care at UCSF. Also ask if 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 may also be certain treatments or procedures that need to be pre-approved by your insurance for the cost to be covered. This is referred to as a pre-authorization. Our office staff will work with your doctor and insurance company to get the necessary pre-authorizations.

If you don’t have insurance, or it is not clear whether you need pre-authorization, UCSF will consider you a self-pay patient and will collect a deposit at the time of your first appointment.

After Your Appointment, Patient Financial Services can help you understand your medical bill, arrange a payment plan with no interest, or get financial assistance (if you qualify). Patient Financial Services can be reached at 866-433-4035 or through MyChart messaging.

Filing for Disability and Leave of Absence
For more information on short-term and long-term disability options, please contact a UCSF social worker. You can do so by calling the Patient and Family Cancer Support Center at 415-885-3693. You can also complete your state disability forms online at edd.ca.gov/disability. You will also often need to complete forms from your employer. To get information about the forms that your employer requires, you will need to contact your employer’s Human Resources Department. Once you have filled out your portion of the form, your doctor or nurse will need to fill out the medical section.
“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

You, Your Family, and Friends

We at UCSF understand that you are the most important member of our health care team. We encourage you and your caregivers to ask any and all questions that will help you fully understand and feel secure about your treatment plan and next steps.

Patients and families facing cancer may need many different kinds of care, expertise and resources. Doctors, physician assistants, and nurse practitioners will provide much of the day-to-day treatment and care. However, there are many other care providers and staff on your health care team. The following section provides an overview of various roles and functions of the people who are available to help you through your treatment.
Doctors
Depending on your type of cancer and the treatment plan that you and your doctors agree upon, you will have one or more doctors who will care for you. Some of the doctors who will treat you are called oncologists and they specialize in treating cancer. In addition to specializing in different types of cancer, oncologists also specialize in particular types of treatment, such as surgery, radiation, or medical interventions.

A medical oncologist is a doctor who treats cancer patients with cancer-fighting medications such as chemotherapy, immunotherapy, hormone therapy, and other targeted drugs.

A surgical oncologist is a doctor who performs biopsies and uses surgery to remove tumors. At UCSF, surgeons are trained to use specialized instruments or minimally invasive techniques such as robotic surgery, laparoscopic surgery or microsurgery.

A radiation oncologist is a doctor who prescribes radiation therapy (beams of high energy radiation or radioactive seed implants) to shrink or eliminate tumors.

An integrative oncologist is a doctor who works with you to develop a holistic treatment plan that includes therapeutic approaches from around the world, including acupuncture, nutrition, and various stress reduction practices. The Osher Center for Integrative Medicine has a number of integrative oncologists working as part of their team. For more information call 415-353-7700.

As you progress through treatment, you may be referred to other specialists who will make recommendations about tests you will need, your treatment plan, and ways to reduce side effects and improve your overall well-being. Because UCSF is a teaching hospital, you may also be seen by doctors receiving advanced medical training, called fellows and residents.

Nurse Practitioners and Physician Assistants
Nurse practitioners (NPs) and physician assistants (PAs) have completed graduate education and serve as an extension of your physician. They work in close collaboration with your doctor and will meet with you independently to discuss your individual care plan, conduct a physical examination, order medication and diagnostic tests, and manage side effects. Nurse practitioners and physician assistants also provide education and information about your cancer and provide follow-up care for cancer survivors.

Registered Nurses
Registered nurses work closely with your physician and other members of your team to carry out your treatment plan. They are trained to help you navigate your care, educate you about what to expect, administer therapy, monitor side effects, and keep track of details related to your treatment. They can answer many of your medical questions and will communicate important information to various members of your care team.

Dietitians
Our dietitians, also referred to as nutritionists, have special training in oncology and nutrition. They will help you follow a healthy diet during and after your cancer treatment based on the latest scientifically sound nutrition research. They can assist you in planning your diet, coping with nutrition related side effects, and answering your questions about cutting-edge findings on cancer and nutrition. You can make an appointment for an individual consultation by calling 415-502-5547, or you can also make an appointment through your cancer doctor’s office. This service is provided at no charge to cancer patients being seen at UCSF. Our dietitians also offer free seminars on topics related to diet and cancer. To find out more about these seminars, please call the Patient and Family Cancer Support Center at 415-885-3693 or go to cancer.ucsf.edu/csc.

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
Exercise Instructors and Counseling
Our exercise instructors can help you regain and maintain mobility, improve strength and endurance, and offset fatigue and depression through physical activities designed specifically for those going through cancer and recovery. Classes, including yoga, healing through dance, core conditioning, and Feldenkrais-based restorative movement, are available free of charge through the Patient and Family Cancer Support Center. To sign up, please call 415-885-3693. UCSF patients may also make a one hour appointment with a certified cancer exercise specialist to create an individualized exercise plan. Call 415-514-6430 to set up an appointment.

Medical Assistants
Medical assistants help with many aspects of care, including measuring vital signs, recording your medical history and medication list, and helping with procedures. Medical assistants can also help you feel more comfortable while you wait in the exam room by bringing you a cup of tea, a blanket, or a magazine to read. They can also inform you of your expected wait time.

Osher Center for Integrative Medicine Team
The integrative medicine team at the Osher Center includes practitioners from many disciplines, including acupuncture, biofeedback, and mindfulness, as well as integrative oncologists, who specialize in cancer treatment. Using a variety of therapeutic approaches, the health care team will work collaboratively with your primary oncologist to come up with a personalized set of recommendations to complement your cancer treatment so as to reduce stress and achieve optimal health and well-being. The Osher Center can be reached at 415-353-7700

Patient Support Corps Student Interns
The Patient Support Corps trains student interns, usually premedical students, to assist patients and families with tasks such as gathering information about their condition, listing questions in advance of medical appointments, and taking notes and recordings during medical appointments. Please make sure to get the approval of those in the room before recording. To request a student intern to help with choosing and prioritizing your questions or taking notes during your appointment, email PSC@ucsf.edu or call 415-476-6004.

Practice Coordinators
Practice Coordinators answer the phones when you call your doctor’s office. They coordinate your care by scheduling your medical appointments, tests, procedures, and surgeries. They often work with your insurance company to get authorization for certain medical services. They can assist you with general non-clinical needs such as information on parking, and can forward your messages to your provider.

Practice Managers
The Practice Manager oversees the day-to-day operations in the Practice where you are being seen and is in communication with the members of your health care team in that Practice. Despite the best intentions and expertise of every person on your medical team, sometimes things happen that may worry or concern you. Sometimes you may find it difficult to bring up these issues directly with your care providers. The Practice Manager can help you sort through and manage some of these issues. Another option is to contact Patient Relations at 415-353-1936. They also have staff dedicated to helping you navigate issues of concern.

If you have suggestions about how to enhance the patient experience, you can contact the Practice Manager directly, or you can also share your suggestions online at ucsfhealth.org/CC-ImprovementIdeas.

Psycho-Oncology
The Psycho-Oncology clinical team is comprised of psychologists and psychiatrists who work with patients and their families to address the challenges of cancer, including stress arising from treatment, relationship concerns, talking to children about cancer, caregiving, as well as insomnia and other symptoms. Psycho-Oncology providers receive specialized cancer training, and they work closely with your oncology team to support your care at
UCSF. Psychologists on the team specialize in counseling and behavioral approaches, while psychiatrists can prescribe medications such as anti-depressants to help cope with the stresses of cancer. Psycho-Oncology also offers a sleep management course and programs aimed at physical and emotional wellness. This service is open to individuals being treated at UCSF and their family members. You can contact the Psycho-Oncology department at 415-353-7019.

Rehabilitation Specialists
Rehabilitation specialists help people recover from physical changes caused by cancer or cancer treatment. They include physical therapists, occupational therapists, speech therapists, and other professionals. For example, physical therapy can help you rebuild the muscles in your arm and shoulder if you have had chest surgery. If you think you can benefit from rehabilitation services, ask your provider about getting a referral. You may also want to check to see if these types of services are covered by your health insurance.

Social Workers
Specially trained in cancer care, our social workers are dedicated to helping patients and families navigate the health care system and manage the many challenges of living with cancer. Social workers recognize that a cancer diagnosis and treatment can impact all aspects of life, from family and social relationships to work and finances. They will assess each person’s individual needs and provide appropriate support. This may include short-term counseling, advocacy, and linkage to community resources. Social workers also provide information and education about insurance, advance directives, palliative care, hospice, family leave and disability benefits, lodging during treatment, transportation, and cancer-related support programs available at UCSF and in the community. You can contact an oncology social worker through your oncologist’s office or by calling the Patient and Family Cancer Support Center at 415-885-3693. More information is also available at ucsfhealth.org/services/oncology_social_work.

Spiritual Care Staff
The spiritual care staff (chaplains) come from a variety of religious backgrounds and provide emotional support to patients and caregivers throughout all stages of illness. They will meet with you, regardless of your religious beliefs. You can also request to meet with a chaplain of a particular faith, and we will do our best to accommodate your needs.

Our chaplains facilitate religious and spiritual rituals, lead meditation sessions, help with memorial service planning, and provide individual and group grief counseling. Spiritual Care Services can be reached at 415-353-1941. You can also reach a chaplain at any time of day or night through our pager system. To page the chaplain, you will need to call the pager number and then, after the prompt, enter your phone number followed by the # sign. A chaplain will then call you back. To page a chaplain at Mount Zion or Parnassus, dial 415-443-2273. To page a chaplain at Mission Bay, dial 415-443-5786.

Symptom Management Service (SMS) Team
The interdisciplinary team at Symptom Management Service (SMS) helps individuals manage their cancer symptoms at all stages of disease, with a focus on comfort and quality of life. They help patients deal with the physical symptoms of cancer, such as pain, nausea, and fatigue, as well as the emotional strain and existential suffering that can accompany a cancer diagnosis. Patients can benefit from these services early on in the treatment of cancer, as well as in the later stages of cancer treatment, and at the end of life. SMS can also help patients manage any ongoing side effects of cancer and cancer treatment after treatment has ended. Another important service offered is Advance Care Planning to help you document your wishes about treatment and care so that they are known to your family and care team. More information is available at cancer.ucsf.edu/support/sms or 415-885-7671.

Other Care Providers within UCSF and Beyond
You may have other important care providers who are part of your medical team. This may include your primary care physician, acupuncturist, or another type of provider. If you have a physician or care provider, who is not part of UCSF, it is important to make sure that they are informed about your care at UCSF. Similarly, you should let your doctors at UCSF know about additional medical care you are receiving.

Recognizing Members of Your Medical Team
If you would like to recognize the exceptional work of one of your care providers or a member of the cancer center staff, you can do so at ucsfhealth.org/thank_an_employee.
Making the Most of Your Office Visit

“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

Taking time to prepare for your visit will help you use your time with your doctor more effectively. Clear communication includes sharing information about your health problems, the symptoms you are experiencing, your goals and priorities, and issues that might make it difficult for you to follow the treatment plan. 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. Below are some suggestions and resources that might be helpful to you. Do whatever feels most comfortable and right for you.

If you would like some help getting ready for your appointment and making the most of your visit, you can contact the Patient Support Corps program. The Patient Support Corps provides a student intern (a pre-medical student) who can help you access information and resources relevant to your condition, brainstorm and type up your questions and concerns before your office visit, and make an audio recording of the visit. This
will require permission of those being recorded. (Video recordings are prohibited without written consent.) Depending on timing and availability, a student intern may be available to accompany you to your doctor’s visit and take notes for you.

To request assistance, email PSC@ucsf.edu or call 415-476-6004. You can find out more information about the program at psc.ucsf.edu.

If a student intern from the Patient Support Corps is not available, you can obtain a similar question-listing service by contacting a nationwide program called Open-to-Options at 888-793-9355 or cancersupportcommunity.org. Open to Options is available in English and Spanish.

If your English is limited or you are speech or hearing impaired, ask your doctor's office for a medical interpreter. This service is provided at no cost to you.

Bring a family member, a good friend, or invite a student intern to the appointment

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. You can also request to have a student intern by contacting the Patient Support Corps at 415-476-6004.

Bring a list of 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 a copy of your questions to your doctor. Make sure to bring up your main questions and concerns, as well as your symptoms and how they are impacting your life.

Take good notes

Take notes during the appointment or obtain permission to make a voice recording of your visit. If you bring a friend or relative with you, let them help you take notes.

<table>
<thead>
<tr>
<th>Date</th>
<th>Symptom/Event</th>
<th>Description/Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nov 16, 2017</td>
<td>Started chemo: Carboplatin</td>
<td>Light nausea - level 2</td>
</tr>
<tr>
<td>Nov 17</td>
<td>Spoke to nurse (Jan) started Zofran</td>
<td>no nausea</td>
</tr>
<tr>
<td></td>
<td>for nausea</td>
<td>some fatigue - need afternoon nap</td>
</tr>
<tr>
<td>Nov 19</td>
<td>Problems with constipation, spoke to</td>
<td>Stool softener: Miralax (1 packet daily as needed)</td>
</tr>
<tr>
<td></td>
<td>nurse Jan. Increase fluids, add fiber</td>
<td></td>
</tr>
</tbody>
</table>

Keep good records

It is not easy to remember it all – so find a way that works for you to keep track of changes in your health, the medications and supplements you are taking, and new tests or procedures. It is also helpful to note the date of any changes, whether it is regarding a new symptom, test, or medication. Keep this information in a place that is easy to access and update, such as your smartphone, laptop or notebook. Having this information with you will make it much easier to provide your doctor with accurate information. It is also 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. The last page of this guidebook has a sheet that you can use for this purpose. This can also be a useful list to share with your doctor, particularly if you are seeing health care practitioners at different facilities. Your symptoms can be tracked very simply in a table, or as a list, that you keep in a notebook or on your electronic device, as shown in the example below.
Set the tone
Let your doctor know how much or how little you would like to participate in decision-making and whether you want very detailed information about all the treatment options or just general information. Also, be sure to inform your doctor of any cultural or religious beliefs that may affect your treatment choices or preferences. You might also let your doctor know of any special vacation plans or life goals you have so that they can be considered when choosing a treatment plan, or deciding on the timing of a particular treatment.

Ask questions
Do let your doctor and care team know if you have questions about your treatment plan, symptoms you are having, ways to improve your health, second opinions, or other issues.

Know whom to contact and how to follow up
Finally, before you leave, find out when you should see your doctor next, and ask about the best way to keep in touch and have your questions answered between office visits.
ABCs of Cancer: Definitions

"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

Some people liken the experience of a cancer diagnosis to being a tourist in a new country where they suddenly have to deal with an unfamiliar world - new medical terminology, rules and regulations, and procedures and tests. Definitions for some of the most common medical terminology that you might encounter as you go through cancer treatment are listed below.

**Adjuvant Therapy**

Adjuvant therapy refers to cancer treatment given after the main recommended treatment. Its purpose is to maximize the effectiveness and success of overall treatment and to reduce the risk that the cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.
Advanced Care Planning

Advance care planning (ACP) involves exploring and documenting your preferences regarding future medical care. The document, which has your written instructions about your preferences for future care, is called an Advance Directive. Making decisions about your future care involves exploring your values and goals and identifying a trusted person to make medical decisions on your behalf in the event that you are not able to do so. Having an Advance Directive helps ensure that your future care is consistent with your stated preferences.

Anti-Angiogenesis Therapy

In order to grow, tumors can release chemicals that cause new blood vessels to form (angiogenesis). These blood vessels then feed the tumor and support its growth. Treatments that block the growth of new blood vessels are called anti-angiogenesis therapies.

Benign

A benign growth or tumor is one that is not cancerous. It does not invade and destroy nearby tissue.

Biopsy

A biopsy is a procedure that involves removing a small amount of tissue, which is then examined for abnormalities.

Blood Cells

*Stem cells,* are found in the bone marrow, the spongy center of your bones. They give rise to your blood cells: white blood cells, red blood cells, and platelets.

*White blood cells,* or *leukocytes,* are part of your immune system and play an important role in fighting infection. When your white count is low, you are at a greater risk for infection. *Neutrophils* are a common type of white cell that play a role in fighting infection. During cancer treatment, your medical team may monitor your *neutrophil count,* which is often referred to as your ANC (Absolute Neutrophil Count).

Red blood cells, or erythrocytes, carry oxygen from the lungs to the rest of the body. Red blood cells transport oxygen on a molecule called *hemoglobin.* During cancer treatment, your doctor may monitor your hemoglobin to determine your red blood cell level. If it is low, you are considered to be anemic, and may have to delay treatment until your red blood cell count goes up.

*Platelets* are essential in the process of blood clotting, thus preventing excess bleeding and bruising. During cancer treatment, your platelet level may be monitored to make sure that you are not at a higher risk for bleeding.

Cancer Stage

The term “stage” refers to the extent of your cancer – how large the tumor is and if it has spread. Most cancers are grouped into four stages: stage I (one) to stage IV (four). Some cancers also have a stage 0 (zero). Some cancers, such as blood cancers and brain tumors, have a different staging system.

• *Stage 0* means that some abnormal cancer cells are present, but that they have not spread. This can also be referred to as carcinoma in situ.
• *Stage I* describes a cancer that is small, has not grown into nearby tissues, and has not spread to the lymph nodes or other parts of the body.
• *Stage II* and *stage III* describe tumors that are larger, have grown more deeply into the surrounding tissues, and may have spread to the lymph nodes - but not to other organs in the body.
• *Stage IV* refers to cancer that has spread to other organs in the body. This is also called metastatic cancer.
Chemotherapy

Chemotherapy treatment is the use of drugs to stop the growth of cancer cells, either by destroying the cancer cells or by stopping them from multiplying. Chemotherapy affects all the cells that are dividing in the body, but will have the greatest effect on cells that are dividing at a faster rate. Since cancer cells tend to divide at a faster rate than normal healthy cells, they are also destroyed at a higher rate. Other cells in the body that divide rapidly include cells in the hair, mucus lining of the mouth and stomach, and certain blood cells. This is why certain types of chemotherapy drugs make some people lose their hair, feel nauseous, and have mouth sores or low blood counts.

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. Treatments studied in clinical trials might be new drugs or combinations of drugs, surgical procedures or devices, or new ways to use existing treatments.

Clinical trials progress in a series of steps, called phases. During phase I (one), researchers test a new drug or treatment in a small group of people for the first time to evaluate its safety, determine a safe dosage range, and identify side effects. In phase II (two), researchers test whether the treatment shows some benefit, such as slowing tumor growth, and additional information is obtained about dosages and side effects. In phase III (three), trials are expanded to include more people, and the new treatment is compared to standard treatment. Phase IV (four) clinical trials are done after the new treatment has been FDA approved to get more information on side effects and find out more about the optimal use of the new therapy.

Each study has its own rules about who can participate. Some clinical trials, for example, may require individuals to be under a certain age or to have a certain type of cancer. Each clinical trial is reviewed by an independent committee to make sure the study is ethical and protects patient rights.

The possible benefits of joining a clinical trial include:
- The treatment being studied might be more effective than standard treatment.
- You will be followed closely by the research team.
- The trial may help scientists learn more about your type of cancer and develop other effective treatments in the future.

The possible risks of joining a clinical trial include:
- The new treatment may not be as effective as standard treatment.
- You may be required to make extra trips to the doctor’s office and do more tests.
- The new treatment may have side effects that researchers did not anticipate.

If you do not qualify for a clinical trial, you may be able to access the treatment through a program called expanded access, also known as compassionate use. Compassionate use allows drug companies to make treatments that are still being investigated and have not been FDA approved available to individuals with serious illness who may benefit from the drug, but who do not qualify for the clinical trial.

Complementary and Alternative Medicine (CAM) – Integrative Medicine

Complementary and alternative medicine generally refers to treatments that are outside the traditional model of medicine that is practiced in the hospital setting. Integrative medicine combines the standard medical approach with healing traditions from different countries and cultures, such as acupuncture and integrative Chinese Medicine, Ayurvedic medicine, meditation, movement-based therapies (yoga), and Mindfulness-based Stress Reduction (MBSR). You can access these services at UCSF through the Osher Center for Integrative Medicine.

CT or CAT Scan

A computerized tomography scan uses a series of X-rays taken from different angles to create detailed three dimensional images of areas in the body. A CT scan can be used to visualize an abnormality, make a treatment plan, or find out how treatment is working. Sometimes a dye, called contrast, is injected into a vein or swallowed to help certain areas show up more clearly. A CT scan can be combined with a PET scan. Together the PET-CT scan can provide detailed visual information about the body that can be used for diagnostic and treatment purposes.
I always dreaded getting scans. This changed when I shifted my perspective and came to see the scans as a gift of vision. I realized that the scan itself changes nothing in my body and that, regardless of whether or not I do the scan, my tumor will have either shrunk or not. Instead, I now see the scan as providing me with the gift of knowledge, allowing me to know what steps I should take to take care of myself.

~Phoebe
than normal cells. A Positron Emission Tomography (PET) scan produces an image that shows where cells are consuming sugar. The areas in your body with highest sugar consumption will show up as bright spots. A PET scan involves injecting a radioactive sugary substance into a vein and then using a scanner to make detailed computerized pictures of areas inside the body to detect where sugar is consumed at a faster rate. A PET-CT scan combines a CT scan, which involves X-ray images, with a PET scan to give more detailed visual information.

**Radiation Therapy**

Radiation therapy uses high-energy particles, generally referred to as radiation, to destroy or shrink cancer cells. The radiation may come from an external source that aims radiation beams at the cancer or it may come from radioactive implants that are placed inside the body near the cancer cells. Internal radiation is also referred to as **brachytherapy**. Systemic radiation therapy uses a radioactive substance that travels in the blood to tissues throughout the body.

**Surgery for Cancer**

Surgery is a procedure to remove or repair a part of the body. Surgery can be used to determine the type of cancer, where it is located in the body, and whether or not it has spread. Depending on the type of cancer, how much it has spread, and its location in the body, some or all of the cancer can be removed through surgery.

**Targeted Therapy**

Targeted cancer therapies involve new treatments that target specific characteristics of cancer cells to block their growth and spread. Because targeted cancer treatments tend to affect specific characteristics of the cancer cell, targeted treatments may have different or, in many cases, fewer side effects than treatments that affect both normal and cancer cells.

**Traditional Chinese Medicine (TCM) and Acupuncture**

Traditional Chinese Medicine can lessen the side effects of conventional cancer treatments and guide you through some of the physical and emotional changes you might experience. TCM cancer treatments may include acupuncture, traditional Chinese herbs and supplements, and lifestyle changes to enhance the quality of life.

**Tumor**

A tumor is a mass formed when normal cells begin to grow rapidly. A tumor can be **benign** (not cancerous) or **malignant** (cancerous).

**Tumor Grade**

Tumor grade is a number that doctors assign to certain types of cancer as an indication of how quickly the tumor is likely to grow and spread. Tumor grade is determined by looking at tumor cells under a microscope and comparing them to normal cells. Tumor cells that most closely resemble normal cells are called “**well-differentiated**” and tend to grow more slowly. Tumor cells that look abnormal tend to grow more quickly and are referred to as “**undifferentiated**” or “**poorly differentiated**”.

**Tumor Marker**

A tumor marker is a substance in the blood or urine that may indicate the presence of cancer or other condition. Tumor markers can help in diagnosis, treatment planning, and monitoring of cancer. Common examples include CA125 (ovarian cancer), CEA (colon cancer), and PSA (prostate cancer).

**Ultrasound**

An ultrasound is a non-invasive type of imaging that uses sound waves that are bounced off internal tissues and organs in the body to create an image called an ultrasound or a **sonogram**. You may also hear this referred to as **ultrasonography**.

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**Notes**
UCSF Programs and Services

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

- Dan

UCSF offers a wide variety of programs and services to patients, family members, and caregivers. Keep in mind that you can use as many or as few of the services as feels right to you. There is no one “right” way to walk your cancer journey. Be attentive to your needs, recognizing that they may change over time. Some patients may benefit from using many of the services listed below, while others may prefer to use only a few. A full listing of the supportive care programs at the cancer center are listed in alphabetical order on the following pages. We hope that you will take time to explore and utilize the services that will be most helpful to you.
Art for Recovery

The Ernest H. Rosenbaum Art for Recovery program brings artists, writers, poets, and musicians to patients at the UCSF Helen Diller Family Comprehensive Cancer Center. You and your family members are encouraged to come and express your hopes, pain, anger, and dreams through words and images in a safe and healing environment. The many different workshops and weekly programs provide an outlet for individuals and their loved ones coping with cancer to express their feelings through drawing, collage-making, journal-making, and music, as well as creative writing and poetry. A weekly Open Art studio at both Mount Zion and Mission Bay is available to anyone dealing with cancer. The award-winning Firefly Project awakens compassion and insight by providing an opportunity for Bay Area teens and UCSF medical students to exchange letters with individuals coping with cancer throughout the school year. More information is available at cancer.ucsf.edu/support/afr or by calling 415-885-7221.

Cancer Genetics and Prevention Program

If cancer runs in your family or you have had cancer before in another part of the body, you may want to consider genetic counseling. The Cancer Genetics and Prevention Program is a comprehensive genetic counseling service for patients and families. Genetic counselors assess personal and family history, provide education and counseling, and offer genetic testing for cancer predisposition genes when appropriate. Based on family history and other cancer risk factors, counselors and doctors provide an individualized risk management program for each patient, which includes recommendations for cancer screening and options for preventive measures. The program can be contacted by calling 415-885-7779 or going to ucsfhealth.org/education/cancer_genetics_and_prevention_program.

Communicating with Your Doctor and Care Team

The Patient Support Corps provides student interns who can assist patients and families with gathering information, listing questions, taking notes, and (with permission) making recordings of medical visits. More information is available at psc.ucsf.edu or 415-476-6004. A similar program, called Open to Options, run by the Cancer Support Community, is also available to work with you by telephone to help you put together a list of questions to ask your doctor. You can contact Open to Options at 888-793-9355 or cancersupport-community.org. Open to Options offers services in English and Spanish.

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, the program helps patients identify personal values that can serve as guiding principles in leading meaningful lives. For more information or to register, call Psycho-Oncology at (415) 353-7019.

Exercise Classes and Counseling

Exercise can help you improve your strength and can positively affect mood and reduce fatigue. Our exercise classes are offered free of charge and are designed for people going through cancer. Classes offered include yoga, healing through dance, core conditioning, and Feldenkrais-based restorative movement. To sign up, call the Patient and Family Cancer Support Center at 415-885-3693. UCSF patients may also make a one hour appointment with a certified cancer exercise specialist to help create an individualized exercise plan. Call 415-514-6430 to set up an appointment.
Fertility Preservation Program

If you’ve been newly diagnosed with cancer and are concerned about your future fertility or desire to build a family, the Fertility Preservation Program at the UCSF Center for Reproductive Health can provide you with prompt, personalized assessment of your situation. Services include fertility preservation through cryopreservation (freezing) of eggs, sperm, or embryos. The multidisciplinary team will evaluate your needs and make sure that your effort to preserve your fertility or build a family is coordinated with your cancer treatment and care. People who have inherited an increased risk of cancer can receive specialized consultation and care, including pre-implantation embryo screening to protect future generations from mutations linked to cancer. Male and female patients can call 415-353-9115 to request a consultation. More information is on the web at myfertilefuture.ucsf.edu.

Friend to Friend Specialty Shop

You can shop for wigs, mastectomy bras, hats, and turbans, as well as other cancer products, such as inspirational books and skin care products in the warm, welcoming oasis of the Friend to Friend Specialty shop. You can call in ahead of time to schedule a free wig trim and get some styling tips. More information is available at 415-353-7776 or online at friend2friend.org.

Health Information for Patients and Families (Fishbon Library)

You can contact a professional medical librarian who can help you get information about your cancer or research your specific medical questions. For more information contact patientlibrary@ucsf.edu or 415-885-7285, or go to tiny.ucsf.edu/medicalquestions.

Improve the Patient and Family Experience

Cancer Center Improvement Ideas

Nobody knows the patient experience better than patients and families. We are therefore turning to you – the experts – to share your constructive suggestions about how we can improve the patient and family experience at the UCSF Helen Diller Family Comprehensive Cancer Center. Let us know how we can better serve you by submitting your feedback and suggestions to ucsfhealth.org/CC-ImprovementIdeas.

Please note that complaints or concerns about your care should be directed to your doctor, nurse or Practice Manager. If these concerns remain unresolved, please contact Patient Relations at patient.relations@ucsf.org or 415-353-1936.

Join the Patient and Family Advisory Council

The Cancer Center Patient and Family Advisory Council’s mission is to bring about change that improves the patient and family experience, facilitates ease of navigation, and fosters healing and wellness throughout all stages of disease and recovery. The council is comprised of patients and caregivers who share their perspective and feedback with cancer center staff and leadership, participate on task forces and focus groups, and share their experiences on patient panels. Council members are required to complete a volunteer training and to fill out an application. If you are interested in serving on the Patient and Family Advisory Council, please email the Advisory Council at AdvisoryCouncil@ucsf.edu.

Improving this Guidebook

We hope you and your family find this guide helpful. If you would like to provide feedback or make suggestions to improve this guide, please do so by sending an email to guidebookfeedback@ucsf.edu.

Thank and Recognize Exceptional Staff

If you would like to recognize and thank an exceptional staff member, please go to ucsfhealth.org/thank_an_employee.
Infusion Center
The infusion centers at UCSF offer Wi-Fi, light snacks, warm blankets, and wireless tablets to make your visit as comfortable as possible. Given the high volume of patients seen each day, it is important to make an appointment for each visit, including blood draws.

When scheduling your infusion treatment, try to avoid making it too close to another activity that might take longer than expected and delay you. If you miss your appointment time, you will be seen at the next open treatment slot and as close to the originally scheduled time as possible.

Below are the phone numbers and addresses of our infusion centers.

- **Infusion Center at Mission Bay**
  415-353-7155
  1825 Fourth Street
  San Francisco, CA 94158

- **Infusion Center at Parnassus**
  415-353-2272
  400 Parnassus Avenue, 4th Floor,
  San Francisco, CA 94143

- **Ida Friend Infusion Center at Mount Zion**
  415-353-7155
  1600 Divisadero Street, 5th floor
  San Francisco, CA 94115

Feel free to bring a visitor to accompany you during treatment. Given space and safety considerations, we request that you bring only one visitor into the infusion center. Additional visitors can wait in the lobby during your treatment. If you bring more than one visitor, they can take turns spending time with you in the infusion center. Children under the age of 12 are not allowed into the infusion center.

Strategies for Stress Reduction:
- **Do what you love!**
- **Exercise, yoga, dance...**
- **Get a massage**
- **Listen to your body**
- **Meditate**
- **Spend time with friends**
- **Walk in nature**
- **Write in a journal**

Patients under the age of 18 must be accompanied by an adult. Although the risk of a reaction to infusion treatment is low, there is always a potential risk, so an adult caregiver must be on site when a minor is receiving an infusion.

If you have scheduled a treatment but catch a cold or develop flu-like symptoms, please notify your provider. Depending on the situation, your treatment may be delayed or you may need to wear a mask during treatment. Visitors may not enter the infusion center if they have a cold.

Interpreting Services
Interpreting services are available to patients at no cost in many languages, including Cantonese, Mandarin, Spanish, and Russian, among others. If your English is limited or you are speech or hearing impaired, please ask your doctor or nurse to request an interpreter for you. To find out more information about in-person interpreters, please see ucsfhealth.org/services/interpreters.

Knitting Program
Enjoy a relaxing afternoon with other cancer survivors while knitting hats, scarves and other beautiful wooly items. Yarn and needles are provided, and expert knitters are there to help you with your creations. Knitting sessions are held weekly at the Patient and Family Cancer Support Center. Call 415-885-3693 for more information.

Lymphedema Management and Risk Reduction
One of the potential side effects of surgery when lymph nodes are removed is a condition called lymphedema, which involves swelling of certain parts of the body (most commonly arms or legs) as a result of fluid accumulation. Lymphedema risk is often associated with breast cancer surgery, but can also occur after surgeries for melanoma, gynecological cancers, head and neck cancer, or any other cancer surgeries involving the removal of lymph nodes. People who develop lymphedema will be referred by their providers to a lymphedema therapist for treatment.

For more information about our Lymphedema Prevention and Management program, call 415-353-7908.
Meditation and Guided Imagery

UCSF offers weekly meditation and guided imagery classes free of charge to individuals living with or recovering from cancer. In these classes, you will learn to harness the power of the mind to better cope with the physical and emotional stresses of cancer. For more information, contact the Patient and Family Cancer Support Center at 415-885-3693.

Spiritual care staff also provide drop-in mindfulness meditation sessions at the locations listed below. For more information call 415-514-4200.

• At Mission Bay, meditation is offered on Monday, Tuesday, Thursday, and Friday from noon to 12:20 PM in the Meditation Room C1401, at 1975 4th Street, near the Children’s Hospital lobby. The meditation room has an adjacent meditation garden and labyrinth. Additional meditation rooms are located near the elevators on the 3rd, 4th, and 5th floors of the adult hospital at 1825 Fourth Street.

• At the Parnassus campus, meditation is offered from noon to 12:20 PM in the Meditation Room (M193) at Moffitt/Long Hospital, 505 Parnassus Ave., next to the information desk.

• Mount Zion has a Meditation Room at 1600 Divisidero Street in the main lobby behind the information desk.

• Meditation rooms provide a space for emotional expression and contemplation, a place that can be visited throughout the day by patients, caregivers, and staff.

Nutrition Counseling and Seminars

Free one-on-one nutrition counseling is offered by our nutrition experts to patients receiving cancer care at UCSF. To make an appointment for a consultation with one of our cancer center oncology dietitians, call 415-502-5547. You can also schedule an appointment through MyChart or your oncologist’s office. Free seminars on the latest diet and cancer related topics are available to the public. To find out more about nutrition workshops, please visit cancer.ucsf.edu/support/csc/nutrition-counseling-and-workshops or call the Patient and Family Cancer Support Center at 415-885-3693.

Osher Center for Integrative Medicine

The Osher Center for Integrative Medicine strives to successfully integrate modern medicine, healthy lifestyle practices, and established healing approaches from around the globe, in an effort to meet the need for a new model of care and daily living that promotes healing and well-being of the whole person - mind, body, and spirit. For more information, please call 415-353-7700, or visit osher.ucsf.edu.

Patient and Family Cancer Support Center

The Patient and Family Cancer Support Center serves as a hub to direct patients to the many resources and supportive programs available to people dealing with cancer. The staff and volunteers can meet with you to help you find support groups and other resources in the Bay Area. They can also connect you to other cancer survivors through the peer support program and direct you to the many support programs listed in this guide. Other services include educational workshops, as well as listings of reliable sources of information on the web. The Patient and Family Cancer Support Center has a site at Mount Zion and at Mission Bay, with public computers for your use, health education materials, and helpful, friendly staff. You can also sign up to receive monthly mailings about upcoming programs and events at UCSF. For more information call 415-885-3693 or visit cancer.ucsf.edu/csc.
Patient Relations
Patient Relations is available to address any questions or concerns that you may have about your experience at the cancer center. However, it is recommended that you first discuss your concerns with your doctor, nurse, Practice Manager, or social worker. If your concerns remain unresolved, the Patient Relations staff or nursing supervisors are available to help you. You can contact Patient Relations at 415-353-1936 or patient.relations@ucsf.org.

Peer Support Program
The Peer Support Program connects you to other individuals with a similar diagnosis or life situation, such as being a young parent with cancer, dealing with a loved one with cancer, or undergoing a particular treatment. Peer support connections can reduce the sense of anxiety and isolation during the initial period of diagnosis and beyond. Peer volunteers can provide practical advice, strategies for coping, and a listening ear. To speak to a peer volunteer or to become a volunteer, please call 415-885-7210 or go to cancer.ucsf.edu/support/csc/peer-support.

Precision Medicine/UCSF500 Cancer Gene Panel
For some patients with advanced cancer, in particular when there is a poor response to standard of care therapy, it may be appropriate to ask your doctor about a new molecular test, called the UCSF500 Cancer Gene Panel test, which is a key component of UCSF’s Precision Medicine Initiative. The purpose of the UCSF500 test is to identify genetic changes (called mutations) in the DNA of your cancer. This information can help identify the exact type of cancer you have. It can also provide information about targeted therapies and clinical trials that may be effective in treating your cancer. UCSF500 test results may also provide information on inherited genetic changes that can increase the risk of developing cancer for you or your family. To understand more about this advanced Precision Medicine test and whether the UCSF500 Cancer Gene Panel could be an appropriate next step in your treatment plan, please talk to your doctor or read more at gmi.ucsf.edu/cancer/#testing.

Psycho-Oncology Service
The psychologists and psychiatrists in the Psycho-Oncology Practice are available to help you and your family manage stress and anxiety related to cancer. Their role is described in greater detail in the “Your Healthcare Team” section of this guidebook. This service is open to individuals being treated at UCSF and their family members. You can contact the Psycho-Oncology department at 415-353-7019. You may also be referred by your oncologist.

Recording Your Memories
The Legacy Project helps people with life-threatening illness make a video recording of their stories, memories, and messages to share with their loved ones. Professional videographers and volunteer interviewers will arrange to meet with you in the comfort of your home or at another location and will record an hour-long interview with you free of charge. After filming, a flash drive or DVD will be mailed to you, so that you can share it with family and friends. For more information about the program, please visit ucsflegacyproject.com.

Smoking Cessation
Quit smoking with help from the UCSF Fontana Tobacco Treatment Center. Group classes are available for a fee. For more information, call 415-885-7895 or go to ucsfhealth.org/tobaccotreatment.

Prayer, as mundane as it may sound, proved to be the most meaningful and sacred form of emotional support.

- John
Social Work

Our social workers are trained to help patients and families navigate the health care system and manage the many challenges of living with cancer. They can help with both practical and emotional issues. This may include short-term counseling around emotional issues that come up with a cancer diagnosis, such as role changes, grief, and parenting. They can also help with practical support, including linking patients and families to community resources and helping with workplace concerns, disability, and lodging. Social workers can also help you fill out an Advance Directive, which is recommended for all patients no matter the diagnosis. You can contact an oncology social worker through your oncologist’s office or by calling the Patient and Family Cancer Support Center at 415-885-3693. More information is also available at ucsfhealth.org/services/oncology_social_work.

Spiritual Care

Spiritual care chaplains provide emotional and spiritual support to patients and their families by providing a compassionate listening ear and facilitating religious rituals and personal spiritual practices. Spiritual care staff facilitate support groups on grief and provide daily mindfulness meditation sessions at the Parnassus and Mission Bay campuses. For information regarding times and locations see “Meditation and Guided Imagery” on page 52 and 52. They can be reached at 415-353-1941 (Mount Zion and Parnassus) or 415-514-4200 (Mission Bay).

Support Groups

Support groups offer patients and their families a venue to meet with others in similar situations, share experiences, and learn from each other. UCSF offers a wide range of support groups including cancer specific groups, general cancer groups, and groups for family members and loved ones. For more information about support groups offered, please visit cancer.ucsf.edu/support/csc/support-groups or call the Patient and Family Cancer Support Center at 415-885-3693.

Surgery Wellness Program

The Surgery Wellness Program is dedicated to improving surgical care for older adults through a patient-centered multi-disciplinary approach. The goal is to prepare older adults for surgery, enhance recovery, and prevent complications from falls, pressure ulcers, and delirium. Currently under redesign, the program will re-open in the summer of 2019. More information is available at geriatric.surgery.ucsf.edu/wellness-program.

Survivorship Wellness

Survivorship Wellness is a program to help survivors of cancer who have completed active treatment at UCSF connect with each other and practice skills to optimize health and wellness after their cancer treatment ends. In this 8 week group program, led by Psycho-Oncology and a multi-disciplinary team, participants will learn tools to help them meet their goals around nutrition, physical activity, managing stress, sleeping well, and promoting sexual, emotional, and spiritual wellness. To learn more or to register, call 415-353-3931 or go to cancer.ucsf.edu/support/survivorship-wellness. Registration and screening is required prior to program participation.

Symptom Management Service Team

The interdisciplinary team at Symptom Management Service helps individuals manage the symptoms of their cancer at all stages of disease, with a focus on improving quality of life. More information about the program can be found on page 27, as well as page 60. They can also be contacted at cancer.ucsf.edu/support/sms or 415-885-7671.
If 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

Advance Care Planning

Advance care planning is a routine part of cancer care and provides a way for individuals to explore and document their wishes about future care so as to better ensure that their wishes are known and honored for the duration of their lives – whether measured in weeks or decades. Advance care planning involves discussing and documenting your wishes and preferences for the types of medical treatments you do and do not want during your life. It also involves identifying someone who can make decisions for you in the event that you are unable to speak for yourself. It is recommended that everyone, regardless of health status, document their wishes so as to better ensure that they live their lives in accordance with their values and stated preferences. The document which contains this information is referred to as an advance directive. You can download a copy of an advance directive at ucsfhealth.org/pdf/advance_health_care_directive.pdf. Once you fill out an advance directive, make sure
What does it mean to be mortal?
It means to be human.
Life and death, two sides of a coin, inseparable, informing each other. It is through grappling with our mortality that we come to better terms with life - for it is in the realization of the inevitability of death that we can seize life.

-Keren

to save it and give a copy to your doctor and others whom you would like to inform of your wishes. Also keep a copy for yourself in a place where you can easily find and update it.

You can also put together an advance directive through a program called PREPARE, prepareforyourcare.org. The PREPARE website uses videos and stories to help people think through their values and goals for medical care. You can use this information to create a summary of your wishes, which can be shared with medical providers, family, and friends. Your wishes about care at the end of life can also be documented through a physician's order for life-sustaining treatment (POLST). A POLST functions as a physician order to other health care practitioners and emergency personnel to follow the instructions of the order. A POLST order can be worn as a bracelet or kept on the fridge. Having the POLST order visible is a way of notifying medical providers of your wishes in the case of an emergency.

Symptom Management Service (SMS)
The Symptom Management Service (SMS) serves all patients with cancer, including low grade, early stage, and advanced cancers. The SMS focuses on palliative care, improving quality of life throughout all stages of disease. The emphasis is on how to help patients live well until they die - whether death is days away or decades from now. SMS can provide care both in the outpatient and inpatient setting. Patients can also get help with advance care planning to make sure that their values and choices are explored, respected, and honored. Their office can be reached at 415-885-7671 or cancer.ucsf.edu/support/sms.

Palliative Care
Palliative care is medical treatment that focuses on providing relief from the symptoms and stresses of serious illness. The goal is to improve the quality of life of patients by treating physical, emotional, and spiritual distress. It can be provided at any point in the treatment of disease and is not dependent on how long someone is expected to live. Palliative care is provided by a team of specialists and is coordinated with the treating oncology team.

Home-Based Palliative Care in San Francisco
The Symptom Management Service also offers home-based palliative care for UCSF patients living in San Francisco who are homebound with serious illness and who are not enrolled with hospice. Home-based palliative care aims to improve the quality of life of patients and families through home visits by physicians, nurse practitioners, and social workers who specialize in symptom management, communication, and safe transitions from hospital to home.

Hospice
Hospice care provides palliative care to relieve suffering and improve quality of life for people who are expected to live for about six months or less. Hospice care involves a team approach that includes medical care, pain management, and emotional and spiritual support tailored to the patient’s wishes. Support is also extended to the patient’s loved ones. At the center of hospice care is the belief that everyone has the right to compassionate care that respects the right of each individual to live with dignity and support. Hospice care can be provided at your home or in a living assisted facility through one of the many hospice organizations in the area. 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 nationwide, as well as by many insurance companies.
**Spiritual Care**

Spiritual care staff offer support to patients, family members, and staff. They also offer memorial service planning and a grief support group for families whose loved ones have died. More information is available at 415-514-4203.

**Day of Remembering**

The UCSF Symptom Management Service, Art for Recovery, and Spiritual Care Services facilitate an annual Day of Remembering Memorial Service. This service is an opportunity for families, friends, caregivers, and UCSF employees to remember and honor those that have been cared for at the UCSF Helen Diller Family Comprehensive Cancer Center. For more information about time and dates, contact 415-885-7671.

**Notes**

"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

There are many different ways to get to UCSF – by car, public transport, shuttle, and ferryboat.

Depending on your type of cancer and the treatment you are getting, you will likely be seen at one of our three main campuses:

- Mission Bay (1825 4th Street)
- Parnassus Heights (400 Parnassus Avenue)
- Mount Zion (1600 Divisadero Street)
Driving by car
Detailed maps and directions to UCSF clinics are available at pathway.ucsfmedicalcenter.org. Information about parking garages, parking rates, and valet parking can be found on the following pages for each campus.

Public Transportation
Useful resources for navigating San Francisco public transportation include:

- [www.511.org](http://www.511.org) or dial 511
- SFMTA – [sfmta.com](http://sfmta.com) or 415-701-2311
- GoogleMaps and Moovit ([moovitapp.com/](http://moovitapp.com/)) are both available as mobile apps you can download onto your phone.

**The San Francisco Bay Ferry** - [sanfranciscobayferry.com](http://sanfranciscobayferry.com/) goes from Jack London Square in Oakland and the Alameda Main Street Terminal in Alameda to the San Francisco Ferry Building Terminal. From there, the KT Muni line goes to Mission Bay, the 38 bus line goes to Mount Zion and the N-Judah streetcar Muni line goes to Parnassus.

**Caltrain** ([http://www.caltrain.com/schedules.html](http://www.caltrain.com/schedules.html))
Caltrain provides commuter rail service along the San Francisco Peninsula through the South Bay to San Jose and Gilroy. Caltrain goes up to the San Francisco Caltrain Station at 700 4th Street. From there, take the KT Muni line to Mission Bay.
Finding Your Way Around UCSF

UCSF Shuttle - Call 415-476-4646 (GOGO), go to LiveShuttle.ucsf.edu, or download the UCSF Mobile app onto your phone, for real-time shuttle information.

The UCSF shuttle service travels between UCSF campuses and is free to UCSF staff, faculty, patients, and their visitors. There is also a shuttle (Red line) that connects the Mission Bay campus with the 16th Street BART station. The shuttle stop is a few feet away from 2970 16th Street and across from the US Bank.

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 to board patrons with mobility challenges. More information about routes and timetables can be found at shuttles.ucsf.edu. To get real-time shuttle arrival and departure information, go to LiveShuttle.ucsf.edu.

Mission Bay
1825 4th Street

Driving by Car
Driving directions and parking information can be found at pathway.ucsfmedicalcenter.org or by calling 415-476-1511. Managing traffic and parking at UCSF Mission Bay can take time, so please factor this into your plans.

Parking
The hourly parking rate at Mission Bay is $4/hour, and the maximum daily rate is $32. Patients with a disabled placard pay a daily parking rate of $7.

Valet Parking will park your car at no charge. However, you will need to pay regular parking fees charged by the garage. To use Valet Parking, drop off your car in front of 1825 4th Street. Valet services are open Monday through Friday, 8 AM – 6 PM, with the latest drop-off time of 3 PM. If you need to pick up your car after 6 PM, you can get your keys at the cashier booth on the north side of the lot (nearest 16th Street.) After 1 am, Campus Security will have your keys.

Public parking options include:
- 1835 Owens St. Garage, located across from the UCSF Ron Conway Family Gateway Medical Building
- 1625 Owens St. Garage, located next to the Mission Bay Community Center
- 1630 Third St. Garage, located just north of 16th Street
- 1500 Owens St. surface lot

Public Transportation to Mission Bay
- The UCSF Mission Bay campus is served by the Muni KT line and #55 bus.
- The Muni KT line stops on Third Street, near Mariposa Street.
- The #55 bus stops on the corner of 4th St. and 16th St., near the 1825 4th St. entrance.

Free UCSF Shuttles to and from Mission Bay (MB)
UCSF shuttles run every 15-30 minutes between Mission Bay, 16th Street BART, and other UCSF campuses. Information about shuttle schedules and routes can be found online at https://campuslifeservices.ucsf.edu/transportation/services/shuttles or by calling 415-476-4646 (GOGO).
ARRIVING to Mission Bay from the following locations:
- From the 16th Street BART Station – catch the Red shuttle, which is a few feet away from 2970 16th Street and across from the US Bank.
- From the Mount Zion Campus – pick up the Gold shuttle at 2369 Sutter Street across from the UCSF Women’s Health Center.
- From the Parnassus Campus – pick up the Blue, Gold, and Grey shuttle at 401 Parnassus Ave.

DEPARTING from Mission Bay (MB) to the following locations:
- To 16th Street BART Station: The Red shuttle leaves MB from 1505 4th Street in front of the UCSF Housing Services Office
- To the Mount Zion Campus: The Blue shuttle leaves MB from 1573 4th Street (west side) in front of the Koret Quad
- To the Parnassus Campus: The Blue, Gold, and Grey shuttles leave MB from 1573 4th Street (west side) in front of the Koret Quad.

Mission Bay TMA Shuttle - www.missionbaytma.org/shuttles-at-mission-bay
The Mission Bay Shuttle service is free to the public and offers routes from the Transbay Terminal and Powell Street BART to Mission Bay. (Please check the website, as routes may change.)
- From the Transbay Terminal, the shuttle stop is at 500 Howard Street (white loading zone)
- From the Powell Street BART, you can catch the shuttle on 5th Street, just before Market Street (white loading zone is between the entry to San Francisco Centre and Market St.)

Mission Bay Jitney (https://ucsf.ridecell.com), 415-476-4646 (GOGO)
Patients can call the Mission Bay Jitney to pick them up or drop them off anywhere within a half-mile radius of the Mission Bay campus from 8 AM – 5 PM on weekdays. They can also request a Jitney ride by stopping at one of the Kiosks in the Mission Bay lobby. Patients can also go online and create an account at ucsf.ridecell.com to order rides.

Caltrain (http://www.caltrain.com/schedules.html)
Caltrain arrives to the San Francisco Caltrain Station at 700 4th Street. From there, cross the street to the 4th & King Street Station to take the KT Muni line directly to Mission Bay.

The San Francisco Bay Ferry - sanfranciscobayferry.com/ travels from Jack London Square in Oakland and the Alameda Main Street Terminal to the San Francisco Ferry Building Terminal. From there, walk to the Embarcadero Station and take the KT muni line to Mission Bay.
Parking
The hourly parking rate at Parnassus is $4/hour, and the maximum daily rate is $32. Patients with a disabled placard pay a daily parking rate of $7.

Valet parking is available at 400 Parnassus Ave. from 8 AM to 5 PM, with the latest drop off time of 3 PM. If you need to pick up your car after 5 PM, follow the instructions at the valet station (and on your valet ticket) to pick up your keys. The valet service is free, but patients must pay regular garage parking fees.

Parking Garages
• Millberry Union Garage is located at 500 Parnassus Ave. There are two garage entrances, one on the north side of Parnassus Avenue and another on Irving Street, near 2nd Avenue.
• Parnassus Garage (a public garage) is located at 350 Parnassus Avenue.

Public Transportation to Parnassus
The UCSF Parnassus campus is served by:
• Muni streetcar line N-Judah, with a stop at Second Avenue and Irving Street
• Bus lines 43-Masonic and 6-Parnassus, with a stop in front of the hospital (N-Judah and 43-Masonic are wheelchair accessible). For more information about Muni visit sfmta.com
Mount Zion
Parking and Transportation Services
415-514-8935

Driving directions and parking information can be found at pathway.ucsfmedicalcenter.org or by calling 415-514-8935.

Parking
The hourly parking rate at Mount Zion is $6/hour, and the maximum daily rate is $32. Patients with a disabled placard pay a daily parking rate of $12.

Valet parking is available at 1600 Divisadero Street from 8 AM to 5 PM, with the latest drop off time of 3 PM. If you need to pick up your car after 5 PM, follow the instructions at the valet station (and on your valet ticket) as to where to pick up your keys. The valet service is free, but patients must pay regular garage parking fees.

Mount Zion Parking and Transportation Services - 415-514-8935
• The UCSF Garage is located at 2420 Sutter Street
• Divisadero Garage, a public garage, is located at 1635 Divisadero Street. For more information about the public garage, call 415-441-5408 or visit www.1635divisaderogarage.com
• Other public parking garages are available nearby.

Public Transportation to Mount Zion
UCSF Mount Zion campus is served by Muni bus lines 2, 38, 24 and 1. (Bus lines 2 and 38 are wheelchair accessible.)
• Bus line 2 stops at the corner of Sutter and Divisadero.
• Bus lines 38 and 24 stop at the corner of Divisadero and Geary streets.
• The California 1 bus line stops at the corner of California and Divisadero streets, three blocks north of Mount Zion. For more information about Muni visit sfmta.com
## Calendar of Symptoms

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## Notes

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