How to make the most out of your doctor’s visit

Cancer patients look forward to their doctor appointments with both anticipation and dread. The fear comes from what they might hear, but they are also eager to have the opportunity to talk with their doctor about the many questions that arise during diagnosis and treatment.

Effective communication with your doctor and health care team does not come easily. It requires planning and sometimes even a rehearsal in order to accomplish everything the patient wants within the limited amount of time available.

**Bring someone, take notes**

“We always like it when a patient brings a family member or friend with a notebook that lists questions and concerns,” said Nam Cho, MD, a radiation oncologist at Santa Clara Valley Medical Center. “Having someone else take notes allows the patient to listen and not worry about forgetting anything. If the patient is alone, we will often write down ourselves what we are saying so that the information will be accurate and complete.”

Laura Ellingson, PhD, a Professor of Communication at Santa Clara University whose research focuses on communication in clinics and hospitals, adds that patients should think in advance about what their priorities are -- what they need to maintain their quality of life. Sometimes, she warns, that means talking about things that make the patient uncomfortable.

“It can be embarrassing to describe bodily functions,” she said, “but patients need to remember that what seems very private to you is routine for health care professionals. The more honest and forthcoming you can be about yourself, the more the doctor can help you.”

Dr. Ellingson suggests practicing out loud your questions that are sensitive so that you become used to saying the words and disclosing intimate details about yourself and how you live.

“We want patients to tell us how they are feeling and what symptoms they are experiencing,” Dr. Cho said. “If they don’t say anything, we assume all is okay and the patient continues to suffer from something we might have been able to manage with a change in medication.”

**Develop a partnership**

This back-and-forth dialogue is key to the most successful model for patient-doctor relationships, according to Dr. Ellingson. “It’s a partnership in which the physician brings expertise but so do the patients who have the best knowledge of their symptoms and pain levels and how they live their lives. The doctor and patient respect each other, explore together options and alternatives, and work together to make decisions.”

When it comes to difficult conversations, both the patient and the doctor have a role in making them effective.
The financial impact of cancer

We usually think about treatments being associated with harmful side effects but have you ever heard of “financial toxicity”? That is a new term that researchers have coined to describe the financial impact of the high cost of cancer treatments which negatively affects both psychological and physical well-being. It may be a fairly new term but certainly not a new issue for cancer patients.

According to the Institute of Medicine, cancer care costs in the US are increasing at an incredible two to three times the rate of other health care costs. A recent survey by the Kaiser Permanente Center for Health Research found that a third of cancer survivors had to borrow money or go into debt to pay for their care. And for 55% of those who went into debt, it was to the tune of $10K plus.

I remember early on in my career when I started hearing stories about cancer patients who experienced severe financial distress. I quickly realized how common it was for even middle-class cancer patients with well-paying jobs and health insurance to easily slip into financial distress as a result of treatment costs, lack of salary from no longer working, inability to obtain adequate disability, and extra expenses associated with cancer (transportation, caretaking, supplements, etc.).

Harder for low income patients

For low-income cancer patients, the financial impact of a cancer diagnosis is even more profound and can be a catalyst for a downward financial spiral. When one of our young adult cancer patients was discharged from the hospital, his mother, who was working as a house cleaner, had to take off time to care for him. That meant no income which pushed her financially precarious household more into debt. Eventually the family was unable to pay their rent and were forced to move. Add homelessness onto a family struggling with caring for a loved one with cancer and the result is an overwhelming array of stressful issues that ultimately impacts on everyone’s health and access to care.

Here in Silicon Valley, with our incredibly high cost of living, the impact of a cancer diagnosis on both low and middle-income cancer patients can be overwhelming. It may be clear that our friend or neighbor with cancer is struggling emotionally but less obvious that financial worries also contribute to their already high level of stress. For someone who has worked and been independent reaching out for financial support can be especially difficult.

At Cancer CAREpoint we understand that a diagnosis of cancer is more than just a medical crisis. It affects a person’s emotional, practical, spiritual – and financial – well-being. Our programs are designed to address these issues and help cancer patients and their families on the road to healing. Your support makes this possible and is always appreciated.

Welcome Sharon Svensson

Sharon Svensson, President of Essex & Drake Fundraising Counsel, has joined the Cancer CAREpoint Board of Directors.

A well-respected fundraising professional in the Bay Area since 1984, Sharon has worked with the San Jose Cleveland Ballet, San Francisco Boys Chorus and consulting firms in development and management positions. She teaches workshops on all aspects of fund development for nonprofit organizations. Sharon has a B.A. in Social Science/Political Science from Long Beach State University and attended graduate school at Texas A&M.

Rob Tufel, MSW, MPH
Executive Director

Cancer CAREpoint is committed to ensuring that at least 80% of revenue is used for the delivery of programs and services.
Our Community Cares

Thank you to our early donors and the many individuals, businesses and community groups that are supporting Cancer CAREpoint and making a difference in the lives of cancer patients and their families.

Cancer CAREpoint, followed by Executive Director Rob Tufel describing today’s activities and current Board Chair Allison Jones Thomson outlining future goals including extending services and outreach into the underserved neighborhoods of East San Jose. Stop by and take a look!

Time Out Clothing in Los Gatos held its fourth annual fundraising event for Cancer CAREpoint in honor of longtime employee Barbara Villanueva. Thank you to store owner Ginger Rowe and her customers for their continued support.

Therapy Salon in Los Altos raised more than $4,000 for Cancer CAREpoint. Donna Spagnuol, Wig Bank volunteer, gives a special thank you to Paige Madrid and Sarah Zebb.

Sima Hilde of New Look Institute, hair restoration specialists in San Jose, generously dedicated one month’s proceeds to support Cancer CAREpoint.

Perfectly pink jerseys were auctioned off during a San Jose Barracuda ice hockey game at SAP Center as part of a “Pink in the Rink” event presented by Kaiser Permanente to support Cancer CAREpoint.

Thank you to Jennifer McRay, owner of Kismet Boutique in Los Gatos, for sponsoring a fundraising and awareness event at the store.

Kribay Radio’s second Shake, Rock and Roll Bunco event was just as successful as the first in raising funds for Cancer CAREpoint and giving local bunco fans a fun game day with cocktails. Thank you to radio personalities Lisa Kreisler and Sam Van Zandt for emceeing and raising awareness of cancer in our community. Mark your calendar for the next bunco event on March 10!

 Legacy donors, the community leaders who were among the first to invest in the mission of Cancer CAREpoint, attended an unveiling ceremony of a donor board at the Resource Center recognizing their contribution to the success of the organization.

Former Board Chair Gay Crawford gave a moving account of the founding of Cancer CAREpoint celebrating National Breast Reconstruction Awareness (BRA) Day with a sold out event at Testarossa Winery featuring a decorated bra contest judged by Olympian Peggy Fleming, Evergreen School District Trustee Sylvia Arenas and KBAY radio personality Lisa Kreisler and a talk by Cancer CAREpoint Board member Kamakshi Zeidler, MD, about new advances in breast reconstruction.

More than $1,000 was raised for Cancer CAREpoint at an Almaden Golf & Country Club Tournament.

There are new books in the Cancer CAREpoint Resource Center library thanks to a $1,000 donation from Los Gatos Lions Club.

Students from Branham High School presented a check to Cancer CAREpoint social worker Amy Goldsbury – the result of fundraising events at the school. Cancer CAREpoint also received a donation from students at Del Mar High School. It’s great when young people take time to help others in the community.

Cancer CAREpoint Board Chair Allison Jones Thomson was recognized as an outstanding fundraiser at the annual Silicon Valley Philanthropy Day sponsored by the local chapter of Association of Fundraising Professionals. Sharing her special day is her mom, Jean Farren Jones.

Cancer CAREpoint received its third grant from the Symington Foundation to support our guided imagery program. Thank you to funder Toby Symington and Cynthia McDonnell, PhD, the inspiring provider of our guided imagery and mediation programs.

Thank you to the Addison-Petulak Jewish Community Center Silicon Valley for inviting Cancer CAREpoint to set up an information table about our services on Giving Tuesday. We also want to thank Carleen Carver and Cecilia Carranza for helping us that day.

World class pianist Katya Grineva performed a benefit concert for Cancer CAREpoint in November and will return to Silicon Valley for another benefit recital at the Montalvo Arts Center in Saratoga on Tuesday, May 10. For ticket information contact Gay Crawford at gayc@aol.com.

More than $3,400 was raised for Cancer CAREpoint at an Almaden Golf & Country Club Tournament.

Cancer CAREpoint received a donation from students at Saratoga High School in honor of our guided imagery and meditation programs.

Students from Saratoga High School presented a donation to Cancer CAREpoint to help fund support programs.

There is new information contact Gay Crawford on Tuesday, May 10.

Almaden Golf & Country Club Tournament.

Wipeout Cancer and Cancer CAREpoint Executive Director Allison Jones Thomson hosted the Wipeout Cancer Sports Day for Kids. Host NBC Bay Area’s Paul Morigi emceed the event presented by Kaiser Permanente at SAP Center as part of a “Pink in the Rink” event for another benefici-concert at the Montalvo Arts Center in Saratoga.

Lissa Kreisler and Katie Grineva performed a benefit concert for Cancer CAREpoint for the Sharks Foundation for a grant of $8,000 to help fund programs for individuals and families living with cancer.

Students from Branham High School presented a check to Cancer CAREpoint social worker Amy Goldsbury – the result of fundraising events at the school.

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Effective patient-doctor communication

"As a doctor, we are constantly looking for signals that tell us what the patient is ready to hear about a prognosis," Dr. Cho said. "We need to provide enough information so that decisions can be made but not so much that we overwhelm the patient. It is okay to talk to us about anything that is scary or worrying them, even if it’s not directly related to treatment or take part in a clinical trial. Feeling more in control also makes it easier to make life-changing decisions.

"We want to know how you are feeling emotionally as well as physically," Dr. Cho said. "It doesn’t mean that you are not being brave, strong and hopeful to discuss what you are scoring." There are many aspects to our lives that make life worth living – relationships, jobs, home life, the ability to care for ourselves and others – and those are as important to discuss with your doctor as your physical condition.

"Just remember that you will have limited time with the doctor, so you need to be as organized as you can be," Dr. Ellingson said. "Be prepared to articulate clearly the three most important issues. If it’s important to you, it should be important to your health care provider."

Increase energy with Qigong

The most recent addition to the Cancer CAREpoint line-up of programs is a weekly Qigong movement class, taught by Gideon Enz and Ellen Blumenfeld. It uses slow rhythmic movements to unify body, energy and mind for more vitality. It can be adapted to fit the physical limitations of cancer patients and survivors. Sign up for upcoming classes at cancercarepoint.org. Qigong classes are offered on Wednesdays, 12 noon – 1 p.m. Yoga is available on Thursdays, 9-10 a.m. and Wednesdays, 4:30-5:30 p.m. and Gentle Movement on Wednesdays 10:30-11:30 a.m. – all at the Cancer CAREpoint Resource Center.

Caregiving is stressful, but rewarding

Being a caregiver to a loved one dealing with cancer is stressful, but taking care of her mom, Helena, for the past few months has been a rewarding experience for Keeley who says she loves having the opportunity to do little things that makes her mother’s life easier and more enjoyable.

After Helena received a diagnosis of pancreatic cancer last spring, her intention was to continue to live alone in Southern California. But after two tough rounds of chemo, it became clear that she needed help so she moved to San Jose to live with Keeley and her husband. Despite chemotherapy and major surgery, the family received word in January that the cancer has returned.

Learning of a less-than-hopeful prognosis was an emotional blow to the family but counseling sessions with a social worker at Cancer CAREpoint and support group sessions with others in similar situations have helped them cope. "Cancer CAREpoint has been extremely helpful in pointing me towards resources I didn’t know existed for cancer patients,” said Keeley. Obtaining a disabled placard for the car, for example, makes it easier to take her mom to the beach or on other outings when she feels up to it.

"The hardest thing to learn as a caregiver is how to balance the desire of the patient to be as independent as possible with your own desire to do as much as you can for someone you love," she said. "The people at Cancer CAREpoint have taught me to trust myself and to ask for help when we need it," Keeley added. "They've been so supportive – I just love those guys!"

Sign up for a counseling session or caregiver support group at cancercarepoint.org.
Local hospitals partner with Cancer CAREpoint

One of the founding tenets of Cancer CAREpoint is the commitment to provide support services to all cancer patients in Silicon Valley no matter where they are receiving medical care. We are extremely proud of the partnerships we have established with local hospitals and health care providers.

Cancer CAREpoint appreciates the financial support it has received from hospitals as well as the opportunity to cooperate on programs such as the Health & Healing Speaker Series that has featured physicians from El Camino, Good Samaritan and Stanford. Cancer CAREpoint is also partnering with hospital sites to deliver programs, such as classes at Palo Alto Medical Foundation in Palo Alto and a Wig Bank at Valley Medical Center.

New Cancer CAREpoint Network

A recent example of our collaborations is the Cancer CAREpoint Network, an interdisciplinary committee of health care professionals, patients, Board members, volunteers and donors. The group discusses the needs of the community and the current and future programs of Cancer CAREpoint.

Members include: Elizabeth Arias, MD, Palo Alto Medical Foundation; Lori Arias, Vice President, Oncology, Good Samaritan Hospital; Sheryl Brown, Cancer CAREpoint Director of Operations; Lan Cao, LCSW, Regional Medical Center; Paula Reed, RN, retired from Palo Alto Medical Foundation; Jennifer Landes, Patient Care Manager, Infusion Center, Stanford Health Care South Bay Cancer Center; Linda Lester, community volunteer; Vicky Meraza-Santos, client; Jo Scott, Manager, Outpatient Cancer Division, Valley Medical Center; Jan Willoughby, Cancer CAREpoint Board member; and David Zittlow, Cancer CAREpoint volunteer. Brad Leary, LCSW, CT, Cancer CAREpoint Director of Patient and Family Services, serves as chair.