

## Survivorship Coalition Q&A 5.6.21

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### Questions Answered Post Seminar

1. I have had two cancers- br ca 1974 and NHL (2004) but my oncologist wants to move me back to my GP. Whom should I trust to follow me and how often?

**Dr. Shapira:** *Seeing your Primary Care Physician (PCP) is key for preventive care, managing chronic conditions and coordination of care. The need for ongoing specialized survivorship care is determined by several factors such as your risk of future cancers and late effects of prior treatments. Discuss this with your oncologist and make sure you understand why they are recommending that you follow only with your primary care physician.*

**Dr. Kim:** *If your oncologist feels you can "graduate" from seeing them, that likely means you're doing well from an oncology perspective. I see that as positive. I know it can be scary to have to launch from their care. Make sure you have an accurate treatment history (your specific diagnoses and treatments) from your oncology team. Discuss with your oncologist about future surveillance (if needed) and risk for late effects so you can then educate your PCP about your specific survivorship plan. Ask Oncology if there are specific reasons or symptoms that are recommended to call them with. Then, schedule a follow up visit with your PCP to communicate this information and that you will no longer be following with oncology. Discuss what they recommend for interval of follow up and how to communicate if needed between appointments. Hopefully when you and your PCP are on the same page, you'll both feel comfortable following up together.*

2. What do you think about assigning a "survivorship" person as part of the medical team at the time of diagnosis? It might help provide hope too.

**Dr. Shapira:** *The concept of a survivorship navigator is already being tested in several centers. It seems fine and may help provide continuity and coordination of care. Creating such positions, however, involves resources and may not be necessary for every person treated for cancer.*

3. In the hospital, the Physician Assistants play a very important role. Do they have a role in survivorship process and if so, how do they fit in?

**Dr. Shapira:** *Physician assistants, nurse practitioners and nurses are well suited to provide survivorship clinical care and are often the clinicians doing so in cancer centers.*

4. How do I work through the fear of the unknown after my treatment?

**Dr. Shapira:** *Fear of the unknown is common and uncomfortable. Start by discussing with one of the clinicians on your cancer team and/or your primary care physician. That*

may give you the confidence and reassurance you need or you may need to consult with a mental health professional.

**Dr. Kim:** This is a common (and scary) feeling that everyone experiences differently. Discuss how you feel with a medical professional-- your oncologist, PCP, therapist, etc. Finding a therapist who you feel comfortable communicating openly with can be very helpful. Your doctors may be able to discuss specific symptoms that worry you and preventive care to help you do pro-active things to keep yourself healthy. I often tell my patients that we cannot control what happened in terms of cancer-- it was unfair, it was difficult, and likely extremely scary-- so let's focus on what we CAN control now like appropriate screening, nutrition, exercise, and mental health support. Respect what your mind and body have been through to get you here. That fear is a natural defense mechanism. Now let's work on how to continue forward so the fear isn't consuming. Try incorporating mindfulness (suggested resources listed below). Don't pressure yourself to be or feel "normal" all the time. You'll have some bad days, but also hopefully more and more good days. My patients tell me that this fear changes over time, and while you may have unsettling triggers here and there, it gets better.

5. Is it ok to record a video visit?

**Dr. Shapira:** Only if you are granted permission. Some clinicians will allow and others not.

**Dr. Kim:** Not sure if practices or institutions have specific rules about this, but always ask your provider first.

6. I am 57 years old. I was diagnosed with metastatic sarcoma two years ago and have just qualified for SSI disability payments. In California does this entitle me to Medicare or Medicaid? How do I compare the level of coverage against my current insurance to evaluate whether to switch?

**Dr. Kim:** This is a question best directed to a social worker or case manager. Perhaps your PCP's office or the cancer center where you are treated has a social worker who you can be referred to?

7. What if your supporting family member doesn't believe in therapy (neither group nor individual), but is clearly stressed out from dealing with my cancer? Is it my responsibility to help them?

**Dr. Kim:** It is difficult to help someone if they are not ready to receive help. Nonetheless, their stress is real and impactful, and they should know that they don't need to go through it alone. If you haven't already directly addressed it with your family member, consider addressing it in an empathic way. Acknowledge your gratitude for their support and the stress they have experienced from the situation, express your concern about their well-being, and suggest resources besides therapy like mindfulness apps, support groups, groups who organized the talk, or talking to their PCP about it.

*Your family member may also not want to stress you further by acknowledging their stress. If you are in therapy or would like to start therapy, go to a therapist yourself, then talk to your family member about if and in what ways it is helpful for you. Everyone processes at their own speed, so sometimes all we can do is try to be empathic and supportive of each other.*

8. Can someone speak to the relationship between sugar and cancer?

**Dr. Shapira:** *There are many stories about this, but no scientific evidence that ingesting sugar will make the cancer grow.*

**Resource Suggestions from Dr. Kim for mindfulness:**

Guided relaxations calm the nervous system by decreasing blood pressure, heart rate, and muscle tension while increasing blood flow. Research shows that when you consciously change your breathing, you can quickly change how you feel as well. Like any exercising, these should be done regularly to retrain and maintain your mind-body health.

**GUIDED MEDITATION**-- try one of these apps on your smartphone. Setting your phone alarm or work calendar for reminders to do this during lunch or before bed are also great ways to schedule it into your day.

**Mind Shift**

Mind Shift is one of the best mental health apps designed specifically for teens and young adults with anxiety. Rather than trying to avoid anxious feelings, Mind Shift stresses the importance of changing how you think about anxiety.

**Smiling Mind**

Free meditation app with age-group specific content that teaches mindfulness to improve overall emotional well-being and decrease stress.

**UCLA Mindful**

With this easy-to-use app, you can practice mindfulness meditation anywhere, anytime with the guidance of the UCLA Mindful Awareness Research Center. Scientific research shows mindfulness can help manage stress-related physical conditions, reduce anxiety and depression, cultivate positive emotions, and help improve overall physical health and well-being.

**Calm** introduces you to mindfulness with 5 minute instructions. It also has relaxation scenes and sounds to support self-guided meditation. *Available for Apple or Android.*

**Headspace** teaches you the basics of meditation and mindfulness in just 10 minutes a day. *Available for Apple or Android.*

**Cureable** is an app that can be helpful in understanding the mind-body connection and pain coping skills. There is a free version with many free and interesting podcasts on pain research and treatments.

## Questions Answered Live within the Seminar

1. I would like to know how to deal with people in our circles having no idea how much our survivorship plays a part in our lives.
2. I have stage 4 colon cancer; I have a chemo infusion pump every 25 days (was every 12 days for 30 treatments); I've had liver cancer surgery and also have kidney cancer. For the rest of my life (I'm 75 yrs old), I will have treatments and continue to live with side effects for the rest of my life. Also, every 3 months I have a PET Scan. What are ways I can keep a positive attitude and keep my family and spirits up?
3. Is it appropriate to write my questions about my cancer care and forward that to my oncologist ahead of my scheduled office visit or relating to the many questions I have as those questions surface? Should I forward that list to my primary care doctor? Do they communicate and share/collaborate on my care?
4. What if the current healthcare system rules do not allow for additional people/advocates/significant others/ spouses to attend appointments because of covid?
5. I felt under informed and lost when my treatment ended. It appeared that expectations from my medical team were that it's time to move on since I'm "cancer free". But some of physical changes and long-term side effects (i.e. ongoing fatigue) are so debilitating that sometimes I wonder whether it was worthwhile to fight my cancer this hard. Why can't what to expect post treatment be communicated early so patients can consider them in their treatment decision?
6. What resources do you recommend for caregivers who have developed compassion fatigue?
7. Is there such a thing as being "cured from cancer" or "cancer free"?
8. How important is it to be followed by a cancer survivorship program such as Stanford?
9. Many cancer survivors have other chronic conditions in addition to cancer, but I think cancer is the scariest. Dr. Kim how do you help patients balance all their medical conditions?