

Skin in the Game: Drs. Sam Siegel x 2



Disclosures:

- ❑ No industry affiliations to disclose





Set our intentions:

- ❑ Share our story
- ❑ Lessons learned in surviving cancer
- ❑ Shepherding a family through cancer
- ❑ Role of the support person
- ❑ Self advocacy
- ❑ Kaiser San Francisco Longitudinal Survivorship Pilot

Shepherding a Family Through Cancer:

- ❑ Can't hide a parent's illness
- ❑ Digestible portions of truth
- ❑ Let kids lead the conversation
- ❑ Conversation is ongoing
- ❑ No one size fits all approach





Shepherding a Family Through Cancer:

- ❑ Give yourself grace, there are no instructions!
- ❑ Different opinions between partners
- ❑ Trauma informed care
- ❑ Remember there are programs to help
- ❑ Providers often don't know about the programs









Support Person's Role/Care Partners:

- ❑ Cancer is happening to the whole family
- ❑ Identify the care partners
- ❑ Connect with organizations
- ❑ Relieving the burden extends beyond illness (ex: financial toxicity)
- ❑ Oncologists and survivorship programs can help develop questions around work
- ❑ Storytelling projects



Support Person's Role/Care Partners:

- ❑ Care partner can play bad cop
- ❑ Run interference with well wishers
- ❑ Delegation of specific tasks
- ❑ Find trusted organizations for relief caregiving if help is needed

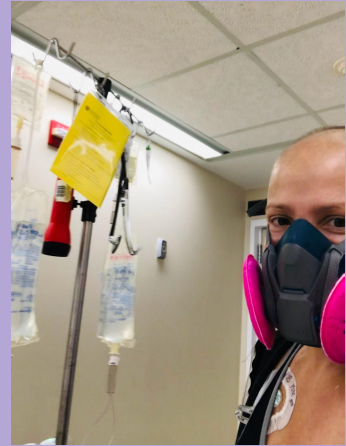
Self Advocacy:

- ❑ Power dynamic never feels equal
- ❑ Second opinions are key
- ❑ Clinical trials are for everyone; acknowledge and let go of narratives that doesn't serve you
- ❑ Awareness of cancer language



Self Advocacy:

- ❑ Letting go of being a likeable patient
- ❑ Share your identity: you do you!
- ❑ Not greedy to want more than not dying
- ❑ Having questions doesn't make you anxious





Self Advocacy:

- ❑ Moving on from toxic dynamics: make up or break up?
- ❑ Bring up the uncomfortable topics
- ❑ Integrative and complementary care coordination
- ❑ Find safe and trustworthy supportive care: MASCC, SIO, CSPN

Manifesting survivorship:





Kaiser San Francisco PCP-ONC CARES:

- ❑ A model where a transition back to primary care isn't required because we never left you in the first place
- ❑ “AWE” philosophy
- ❑ Patient remains at the center, whole person health regardless of stage
- ❑ Shift from problem focused to anticipatory guidance
- ❑ Conversations are dynamic, multidisciplinary
- ❑ Repetition built in the model
- ❑ Laying the groundwork for Survivorship/Supportive care medical training programs



Kaiser San Francisco PCP-ONC CARES:

- A model incorporating all aspects of the cancer experience
- Starts at diagnosis
- Rooted in Vitality: Not dying is not the same as fully living
- What are you living for? What gets you out of bed in the morning?
- Talk about the “death thing”
- Work assessments
- Family
- Whole person health
- CRCI
- Supportive care, cancer rehabilitation
- FCR

Take home points:

- ❑ Cancer is no longer a bad word
- ❑ We need processes to support all of the lives we're saving
- ❑ Patients deserve to be seen in the context of their lives
- ❑ Longitudinal survivorship (beginning at diagnosis) is the future
- ❑ Shift the focus from mortality to vitality!

