



The Challenges of Advanced/Chronic Cancer Survivorship

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A Little About Me

- ▶ I've been a physical therapist since 2004, an outpatient clinic director and most recently enjoy teaching the importance of exercise and community to cancer survivors
- ▶ I was diagnosed with synovial sarcoma of the diaphragm and pleura of the left lung in 2014 while pregnant with our third child
- ▶ Following initial treatment, I was in "remission" for 8 months. I have since had 7 relapses
- ▶ Treatment has consisted of several thoracotomies, rib and partial diaphragm removal, adrenalectomy, 50 radiation sessions, 4 types of chemo and participation in 2 phase 1 CAR-T trials out of Saint Louis
- ▶ I am currently 2 ½ years NED



Specific Challenges I Faced



- ▶ I was diagnosed with a rare cancer. Sarcomas make up 1% of cancer diagnoses and there are 30 subtypes
- ▶ I was initially diagnosed during pregnancy. My initial surgery was limited by an unknown diagnosis. My "suspected" 2 cm tumor was actually 13 cm and removed with negative, but slim margins
- ▶ Research and treatment is outdated for sarcomas. The "gold standard" of care is initial treatment with doxyrubicin and ifosfamide ... a chemo first developed and unchanged since 1988
- ▶ As initial treatments failed, we looked into clinical trials, all being held out of state. The clinical trial involved a 2 ½ month stay for transplant and weekly visits for 3 months thereafter

Specific Challenges My Family Faced Diagnosed As a Young Adult

- ▶ I had a 6 year old, 3 year old and newborn at home to care for
- ▶ We lost our additional family income as a full time physical therapist. Thankfully, my husband carried the health insurance at that time
- ▶ “My tribe” of family and friends had to take time from their jobs and families to attend doctor appointments, chemo infusions, inpatient stays and travel to Saint Louis
- ▶ Treatment and travel came with significant extra financial burden



Challenges of Young Adult Cancer with Kids



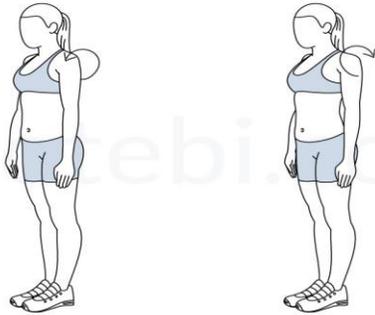
My Dream Oncology Team Would Consist Of:

- ▶ A social worker assigned at diagnosis for patient and primary caregiver
- ▶ A discussion with my medical team on how I want to be involved in my care
- ▶ With the diagnosis of a complicated or advanced care, a discussion toward the beginning of treatment regarding participation in clinical trials
- ▶ Open communication between specialists
- ▶ A palliative care referral at the onset of an advanced diagnosis
- ▶ At least 1 initial dietician consult to include optimal nutrition during treatment and ideas when "optimal" nutrition isn't possible
- ▶ At least 1 physical therapy consult to discuss the benefits of exercise for endorphin release, limit loss of muscle mass, pain control and decrease chemo associated fatigue

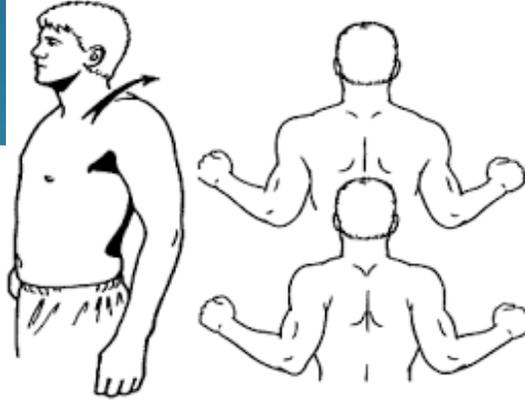
As a PT, I knew the Importance of Exercise, but these are the Mantra's I Lived By:

- ▶ Move everyday! Non-traditional activities that count for movement: walking to the mailbox, performing sitting exercises during commercial breaks, try repetitive sit to stands from a kitchen chair, checking your posture (instead of focusing on a bald head) as you pass the bathroom mirror
- ▶ Exercise recommendations vary from 20 minutes 6x per week or 30 minutes 5x per week. People often forget that these increments can be further broken down. Four (5 minute) walks count!
- ▶ Balance and posture exercises can be performed at the kitchen counter and standing ... avoidance of falls post surgery and chemo fog is so important ... balance exercises can speed your recovery
- ▶ GIVE YOURSELF GRACE !!

My 5 Favorite Exercises For Low Energy Days



Posterior shoulder Rolls



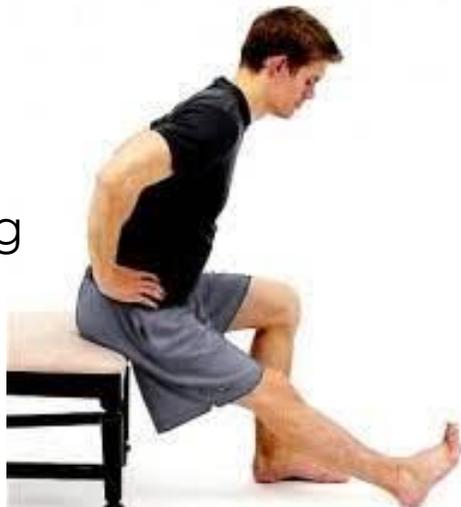
Posterior shoulder rolls



Exercises: 10 repetitions

Stretches: Hold 30 seconds, repeat 3 each side

Seated Hamstring Stretch



Seated Trunk Rotation

Take A Look and Spread The News

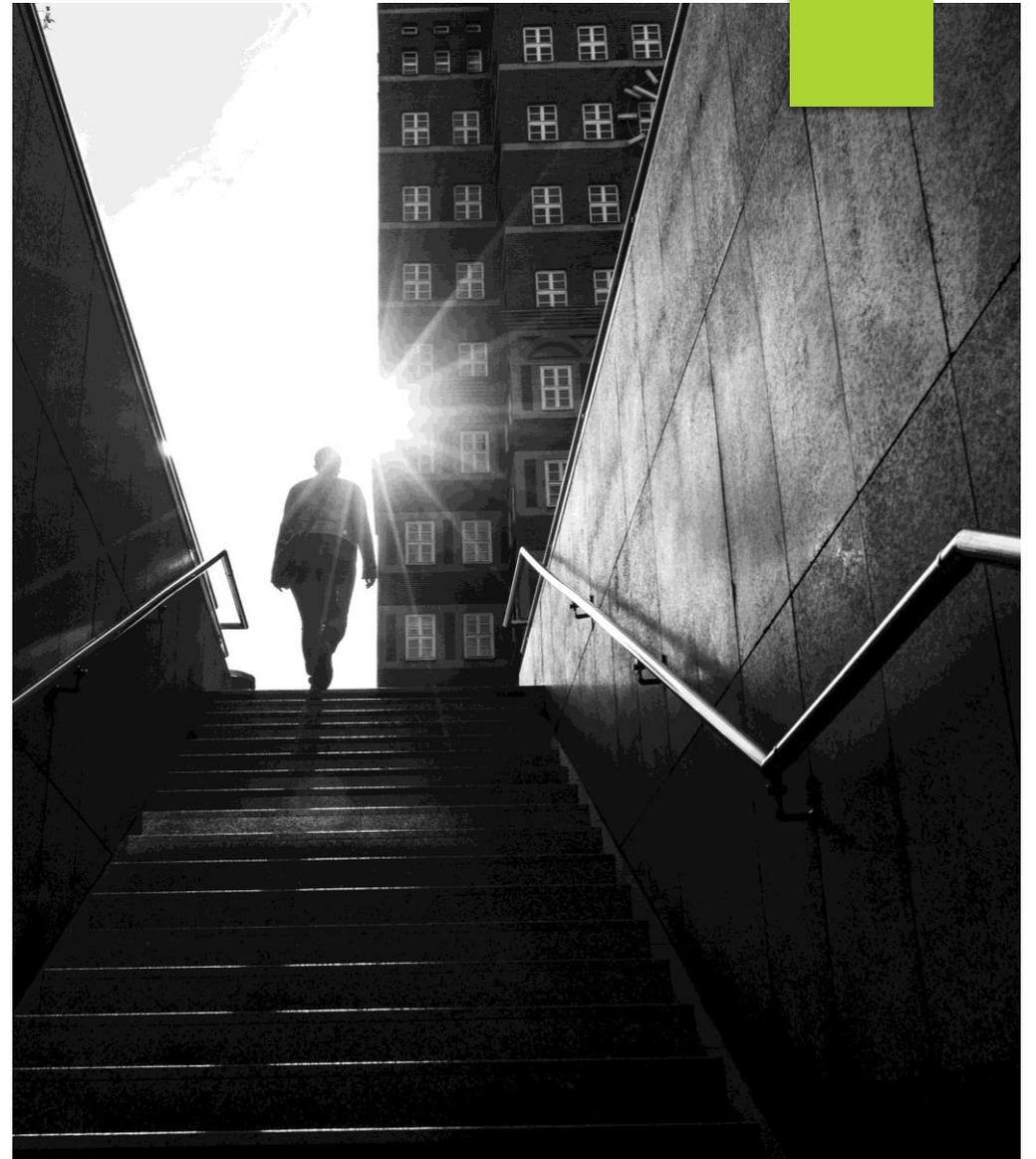
www.loveblackbird.com



We are three young adult survivors of rare and aggressive cancers, warrior women who are learning to thrive and are passionate about supporting others. This is a place for cancer patients, but also those who love someone going through it. We'll talk about cancer, life, love, hardship, and triumphs. Welcome, we're sorry you've needed to find us, but we're so glad you're here!

Empathy for the Patient and Family

- ▶ “In the medical system a human being is split up into specialties and the person is lost in sterilized clinical correctness. Empathy is a form of recognizing the complete and unique person.”
George H. Metastatic cancer patient
- ▶ Diagnosis feels like a death sentence.
- ▶ People need time to understand that they can live with cancer.
- ▶ As they cope with grief, inject some hope.
- ▶ Miracles do happen!



What is Quality of Life?

- ▶ “Everything can be taken from a man but one thing: the last of the human freedoms – to choose one’s attitude in any given set of circumstances, to choose one’s own way.
- ▶ Different meanings for different people... ask them
- ▶ Cancer does not define you...how do you define yourself?



BUILDING HOPE & TEACHING RESILIENCE

“Every Good Thing Counts,” Kate Sommer

Activity

Nutrition

Connection

Play

Spirituality

Caregivers Are Patients Too

- ▶ DX multiplies a caregiver's stress, roles and fears
- ▶ Minimizes their finances, rest, and connections
- ▶ May lose the person they love the most.



Caregivers Have Needs Too

- ▶ Respect
- ▶ Clear communication
- ▶ Support
- ▶ Breaks from caregiving
- ▶ Resources
- ▶ Help

And What About the Healthcare Team? Empathy for Yourself

The Challenges

- ▶ Surrounded by fear and pain
- ▶ Being unable to “fix” problems
- ▶ Loving people who die
- ▶ Grieving
- ▶ Maintaining your empathy
- ▶ Avoiding burnout

What Helps

- ▶ Do your best to leave work at work
- ▶ Have someone to talk to
- ▶ “Every good thing counts”
- ▶ Focus on the good; celebrate success
- ▶ Grieve the losses
- ▶ Take vacations and play
- ▶ Develop a personal spirituality