

Post-Diagnosis & Quality of Life throughout the Cancer Journey

Goal: Assure the highest quality of life for Kansans who have been diagnosed with cancer during and after treatment.

Cancer survivors are at greater risk for recurrence and developing second cancers due to effects of treatment, lifestyle behaviors, genetics or risk factors that contributed to the first cancer. Cancer survivors can help enhance their quality of life, maintain their health and improve survival. About 15% of cancer diagnoses happen before the age of 39.²¹ Survivors of childhood cancer need lifelong treatment as they are more likely to have side effects from some treatments. These side effects can come from the differences in the types of cancer and the treatments being more intense. These reasons can also lead to better response to certain treatments in children as well.²² Cancer is the second leading cause of death in children ages 1-14, only after accidents.²³

While prevention is key to the public health response to cancer among adults, little is known about how to develop evidence-based interventions to prevent cancer among children. Further, there are no nationally recognized cancer screening guidelines to detect childhood cancers in their early stage.

²¹ Pandya, P. (2019, March). Cancer Survivorship Among Kansas Adults, BRFSS 2016. Topeka; Kansas Department of Health and Environment.

The American Cancer Society medical and editorial content team. (2019, October 14). What are the differences between cancers in adults and children? American Cancer Society. Retrieved November 22, 2022, from <https://cancer.org/cancer/cancer-in-children/differences-adults-children.html>

²² The American Cancer Society medical and editorial content team. (2019, October 14). What are the differences between cancers in adults and children? American Cancer Society. Retrieved November 22, 2022, from <https://cancer.org/cancer/cancer-in-children/differences-adults-children.html>

²³ The American Cancer Society medical and editorial content team. (2020, September 18). Key statistics for cancers in young adults. American Cancer Society. Retrieved November 22, 2022, from <https://cancer.org/cancer/cancer-in-young-adults/key-statistics.html>

Objective 20a. Quality of Life - Improve the physical and psychosocial health of people who have had a cancer diagnosis and their care givers.

Objective 20b. Quality of Life - Increase cancer care team’s knowledge and access to resources supporting the physical and psychosocial health of cancer survivors.

Performance Measures (KS BRFSS & KCP Survivorship Workgroup Notes and Activity Evaluation Plans)

1. Adults aged 18 years and older who have ever been diagnosed with cancer who report that poor physical or mental health kept them from doing usual activities, such as self-care, work, or recreation, on 14 or more of the past 30 days
2. Number of cancer survivorship resources and programs implemented and promoted through KCP and KCP members’ organizations
3. Number of multidisciplinary health-care team members who participate in continuing education and professional development opportunities offered by KCP members

Baseline:	Target:
11.5% (2021)	10%
16 (KU Cancer Center)	18
522	600

Strategies

1. Identify and adapt existing national organization materials to provide professional education with CMEs/CNEs that includes information on the treatment, financial, emotional, and vocational needs of those living with stage 4 metastatic cancer.
2. Complete an environmental scan to assess current data, determine best practices, identify/develop curriculum and provide free professional education with CMEs/CNEs that includes physical activity and nutritional guideline, supporting care, and aspects that focus on cancer survivors across the cancer care trajectory.
3. Promote or develop professional education with CMEs/CNEs that includes regionally specific disparate populations and targeted evidence-based practices to improve survivors’ quality of life.
4. Promote CMEs/CNEs through the Brief Tobacco Intervention Online Training for clinicians to improve the availability, accessibility and effectiveness of tobacco cessation services for cancer survivors.
5. Enhance the KCP website to include a user-friendly web page with resources and programs to inform cancer survivors about physical activity, nutrition and the Kansas Tobacco Quitline.

Carly Flumer

Carly Flumer was diagnosed with Stage I metastatic and refractory papillary thyroid cancer at the age of 27 and again at the age of 31. She received her master’s degree from Boston University in Health Communication while going through her first year of treatment, including multiple surgeries and radiation. While being diagnosed with the “C” word at such a young age was a surprise, as it would be to anyone. She found strength, support, and inspiration in sharing her cancer journey on social media. As a result of her health outcome, she looks to advocate for other cancer patients through education, research, and health literacy. She believes that there is power in developing a strong relationship with your care team, and having your provider understand your values and morals as a person, as well as recognizing what you are looking to get out of your cancer journey besides a cure (i.e. maintaining your quality



of life). Finally, she believes in asking questions of your care team (there are no stupid ones!) and expressing what you need of both your care team and your support system.

Treatment Summary/Survivor Care Plan

Treatment Summaries and care plans should contain the required American Society of Clinical Oncology components plus recommendations related to encourage positive mental health, tobacco cessation, physical activity, diet, and other healthy lifestyle behaviors to decrease the risk of cancer recurrence or other chronic diseases.



Source: Stanford Medicine

Treatment summaries will include information about care history: treatments you received, medication doses, surgeries, or any additional treatments that were given. Survivorship Care Plans organizes information about your recommended follow-up care plan. This can include how often you should have check-ups, the types of tests you will need, potential long-term late effects of the treatments received, and suggestions for healthy living.²⁶

Objective 21a. Treatment Summary/Survivor Care Plan--Improve access to survivorship care for cancer survivors in Kansas.

Objective 21b. Increase cancer care team’s knowledge and access to survivorship care from diagnosis through the lifespan.

Performance Measures (KS BRFSS & KCP Survivorship Workgroup Notes and Activity Evaluation Plans)

1. Patients who report receiving treatment summaries.
2. Cancer screening rates in cancer survivors.
 - a. Breast cancer screening
 - b. Cervical cancer screening
 - c. Colorectal cancer screening
 - d. Lung cancer screening

Baseline:	Target:
41.2% (2021)	50.0%
75.7% (2020)	80.0%
91.4% (2020)	95.0%
83.1% (2020)	90.0%
30.0% (2021)	35.0%

Strategies Related to Adult Cancer Patients

1. Collect information, resources and data from partners and organizations across Kansas that provide cancer survivorship programs, services, and support. This could include number of resources utilized, participants and survey responses from programs, tool kits accessed.
2. Educate cancer survivors to ask for treatment summaries and care plans that include cancer screening and follow-up and resources to promote positive mental health, tobacco cessation, physical activity,

²⁶ Asco cancer treatment and survivorship care plans. Cancer.Net. (2022, March 14). Retrieved November 30, 2022, from <https://cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>

nutrition, and other healthy lifestyle behaviors to decrease the risk of cancer recurrence and other chronic diseases.

3. Provide a list of resources to aid providers in completing a cancer treatment summary and facilitate resources for the promotion of healthy lifestyle behaviors.
4. Identify and promote activities that target increasing rates of cancer screenings for survivors and providers to engage in. This includes utilizing the Early Detection Works Program.
5. Provide resources and professional development on the Kansas Cancer Partnership website.
6. Identify and adapt existing resources to provide free professional education with CMEs/CNEs on the importance of treatment summaries/summary of care and ways to improve provider-provider and provider-patient communication.

Press On Fund

Strategies Related to Childhood Cancer Patients (ages 0-19 years)



1. Increasing the cancer survivor and caregiver's awareness and access to survivorship resources and services by promoting existing resources.
2. Develop an education campaign for adult survivors of childhood cancer about the role of care plans and resources for healthy lifestyle behaviors to decrease the risk of cancer recurrence and onset of other chronic diseases.
3. Identify and promote free professional education with CMEs/CNEs that includes use of care plans for childhood cancer survivors, and resources for family and caregiver supports.
4. Establish a data source and collect data to determine the needs of adult survivors of childhood cancers and the extent that the role of coordinated care plans is understood.
5. Provide resources and professional development on the Kansas Cancer Partnership website.

Layla Story by her mother Jessica Beckstrand

Layla was diagnosed with stage 4 neuroblastoma at 18 months old. Her hair was straight and so blonde it looked white. She had a big toddler belly that jiggled when she ran. Layla's laugh was louder than a freight train and her smile was bigger than the world.



On October 29, 2015, during a diaper change, her dad and I noticed her big toddler belly distended to one side instead of in the middle. Concerned was an understatement. Having the distention on the right side, we had fear of an enlarged liver. I took her into the nearest hospital to get an ultrasound, while her dad stayed home with her 3-year-old brother, and within 15 minutes we were on the phone with the chair of the hematology-oncology doctor at the children's hospital who told us the most heartbreaking words,

‘We think Layla has neuroblastoma, an abdominal cancer.
I need you and her to get to the hospital right now.’

Those words, that sentence, is etched into my soul. It became a part of who I am as a momma. Our entire four-person family was turned upside-down, inside-out and stretched beyond anyone's wildest dreams. For the next almost two years, we had to watch, while only being able to hold her hand, as we laid her life into the hands of the best pediatric oncologists there are.

Cancer is the number one cause of death by disease in children in the United States.

Layla went through the ringer. Six rounds of chemotherapy. The tumor was the size of a small football and had metastasized into all the major bones in her body and surgery to remove it. She had 12 days of radiation to her abdomen and spine, more body scans, and fevers than I can count, 38 blood and platelet transfusions, two stem cell transplants and six rounds of immunotherapy.

In children, ‘done with treatment’ does not mean done with side effects or worry.

In February 2017, Layla was declared done with treatment. The lifelong effects that Layla will have as a result of front-line treatment is nothing short of debilitating. Survivorship for kids with cancer are told secondary cancers, hearing loss, heart disease, organ troubles, fertility struggles, hormonal imbalances and mental health struggles, are what they have to plan for. Over 90% of children that 'survive' cancer will have one or more of these secondary issues later on in life. The longer these children live, the higher the risk of developing side effects.

Layla is now a healthy 8-year-old girl in 3rd grade. She only remembers the good parts of the hospital, how she was treated by the staff, the bond that she formed with her brother taking care of her. She loves the outdoors, reading fiction books, visiting historical places and her family. Because of her treatment, Layla has hearing loss. She also has over fifty percent chance of developing a secondary cancer along with heart or liver disease and thyroid issues. It's not a matter of if, it's when.

Childhood cancer is not rare.

I want people to know is childhood cancer may be statistically rare, when you compare it to the adult population, but it is not rare. One in 285 kids will be diagnosed with cancer. There are more types of children's cancers than there are adult cancers. Research for childhood cancers needs to be at the forefront of what is funded at the state level and in the country. Seeing progress is the best way for us families to have peace of mind. And our kids deserve the best.

Palliative Care Program KDHE

Palliative and Hospice Care

Palliative Care: According to Kansas statute 65-1,260, "Palliative care' means an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Unlike hospice care, patients may receive palliative care and curative care (cancer-specific treatment) at the same time.



Hospice Care: The National Hospice and Palliative Care Organization describes end of life care as being for someone with a serious illness and a life expectancy measured in months, not years. Treatments are aimed at relieving symptoms, with the goal of comfort rather than a cure. They are not receiving curative care in these months.

The End-of-Life Nursing Education Consortium (ELNEC) project was developed by nationally recognized palliative care nursing experts to provide comprehensive information about palliative care and end-of-life nursing. Nineteen palliative care community champions decided to move forward to develop a 4-session ECHO series in collaboration with KU Telehealth/Project ECHO, KU Area Health Education Centers, the Masonic Cancer Alliance and Wichita Medical Research & Education Foundation.

Objective 22. Palliative and Hospice Care - Improve Kansas scorecard for access to Palliative Care services, as measured by Center to Advance Palliative Care.

Performance Measures (ELNEC attendance reports & Center to Advance Palliative Care)

1. Number of one-day ELNEC course attendees
2. Number of two-day Train-the-Trainer ELNEC course attendees
3. Number of one-day APRN ELNEC course attendees
4. Kansas counties providing professional educational opportunities in palliative care
5. Kansas palliative care report card

	Baseline:	Target:
1. Number of one-day ELNEC course attendees	1033	1100
2. Number of two-day Train-the-Trainer ELNEC course attendees	206	300
3. Number of one-day APRN ELNEC course attendees	73	90
4. Kansas counties providing professional educational opportunities in palliative care	26	35
5. Kansas palliative care report card	C	A

Strategies

1. Collaborate with the Palliative Care Team in KDHE to recruit and educate more Palliative Care practitioners in Kansas.
2. Collaborate with the Palliative Care Team in KDHE to provide educational trainings to practitioners and survivors.
3. Conduct an environmental scan that includes a heat map of providers and resources that are available.
 4. Promote attendance the 2-day ELNEC train-the-trainer course to train palliative care “champions” to drive local system change by recruitment through state and regional coalition partnerships.
 5. Implement statewide APRN 1-day ELNEC training in primary palliative care techniques/skills by offering in-person and internet-based courses.
 6. Collaborate with the Palliative Care Team in KDHE to increase the number and geographic dispersion of attendees at the 1-day ELNEC training course on palliative care for health care professionals by offering in-person and internet-based courses.

Treatment Standards

Treatment standards are evidence-based standards to provide guidance for best practices in cancer care. These can be used to inform policies and procedures in the healthcare setting, internal quality assessment, and external quality monitoring.²⁷

Objective 23. Treatment Standards - Increase the number of cancer patient care facilities in Kansas participating in nationally recognized quality improvement programs.

Performance Measures

1. The number of cancer care organizations across Kansas that participated in national performance and evidence-based standards program including but not limited to American College of Surgeons Commission on Cancer accreditation program, American Society of Clinical Oncology’s Quality Oncology Practice Initiative Certification Program or other quality/performance standards program.

Baseline:	Target:
15 care organizations	20

Strategies

1. Actively promote and align quality standards of care with national guidelines.
2. Support local/regional collaborations among cancer centers to create a community of practice supporting evidence-based cancer care.

²⁷ Cancer care standards. ASCO. (2021, October 20). Retrieved November 30, 2022, from <https://old-prod.asco.org/practice-patients/cancer-care-standards>
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3. Support cancer centers and hospitals throughout Kansas in their application for evidence-based quality improvement program accreditation or certification.
4. Increase provider use of evidence-based treatment guidelines by and through tele-mentoring, promoting awareness, education and advocacy efforts to increase the number of patients receiving the highest quality of care.
5. Support the development and implementation of system changes that improve quality of care for Kansas cancer patients at the local or state level, including data tools that help identify quality deficits and electronic health record tools that assist providers in delivering timely and accurate oncology patient care.
6. Engage with partners to identify and strategize to address variations in care due to access to screening, biomarker directed therapy, and healthcare disparities.

Tracy Mason

Tracy had gone to the local hospital when she noticed she needed a mammogram. She left this hospital with the information that she could have either an infection or an invasive cancer, and to come back in 30 days to see if the potential infection had cleared. Tracy was not satisfied with that answer and she called KU the next day. At KU, many tests were performed. She had several mammograms and ultrasounds, but nothing was picking up this 10cm tumor that was growing rapidly. Tracy was finally diagnosed in 2019 with a rare type of breast cancer: invasive lobular pleomorphic carcinoma HER2+.



This cancer is one that is mainly found in women older than 65 and it is one that grows rapidly. Her cancer grew in 5 days with no sign of stopping. Tracy found it a relief to finally know what is happening with her body. Her oncologist wanted to start chemo the next week, in preparation they did ECHOs, EEGs, Bone Scans, and PET Scans. She had her port placed and within 7 days, she had an allergic reaction to the port. She had a year's worth of chemo and 33 rounds of radiation. Tracy had mastectomies and countless surgeries such as reconstruction.

Looking back, she would not change anything. She believes that was equipped to handle a hard diagnosis, as she had underlying cardio and neuro muscular problems. She was not afraid to do what she had to do to survive, she was prepared to be stubborn. This diagnosis made her stronger than she already was, she had to be. She met some of the greatest people through cancer. She hopes that people who read this story get hope out of her experiences. She wants everyone to know that if she can do it you can too as well as it is okay to give yourself some grace.