



Passport
for Care®

with the CHILDREN'S
ONCOLOGY GROUP

The Transition to Adulthood

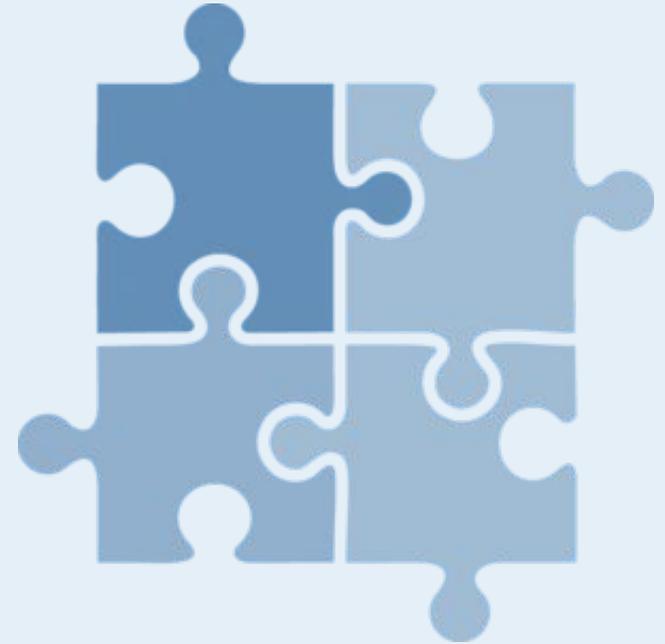
Healthcare Responsibilities After the Childhood Cancer Experience

Ellen Shohet, MN, RN
Texas Children's Hospital

Quick Poll!

Where do you fit into the puzzle?

- A. I Know a Cancer Survivor
- B. I Am a Cancer Survivor
- C. I Treat a Cancer Survivor



Childhood Cancer By the Numbers

- 80% of children survive
- 500,000 cancer survivors in the US
- 70% of survivors have late effects of treatment
- 150 potential late effects of their cancer treatment

What is SURVIVORSHIP?

- Post-cancer support, intervention, and care
- Goals of Survivorship:
 - Acknowledge the enormity of the cancer experience
 - Guide childhood cancer patients toward healthy, fulfilling lives post-treatment
 - Encourage ongoing medical and psychosocial care

Into the Unknown: Adulthood

- Challenges in transitioning from child patient to adult survivor
 - Insurance & Insurability
 - Finding knowledgeable adult providers & subspecialists
 - Cost & access to care

Taking the Reins

SURVIVORS

- Know your story
- Be an active participant in healthcare decisions
- Learn about survivorship & your next steps

HEALTHCARE WORKERS

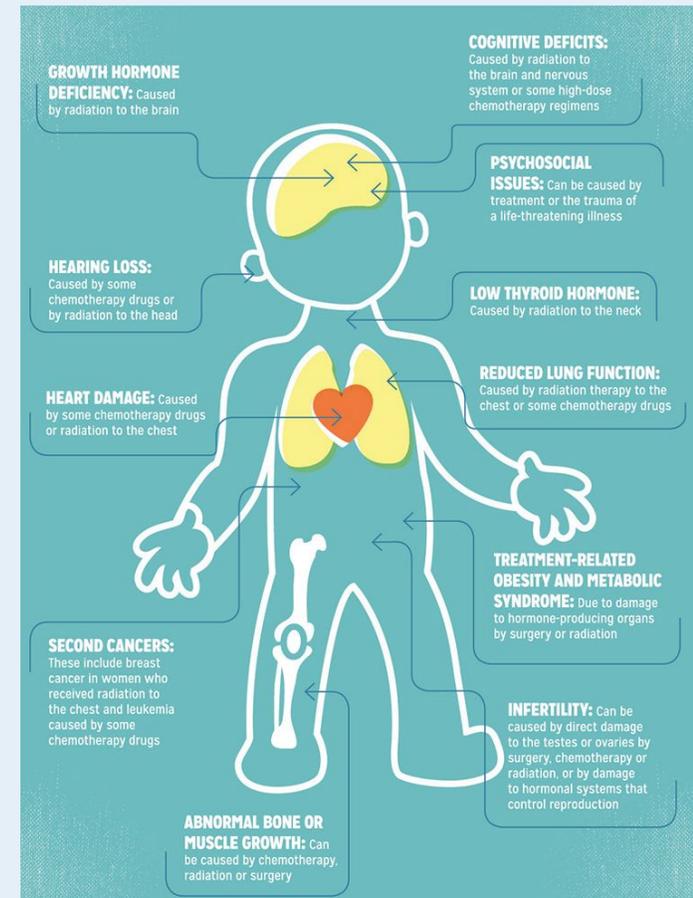
- Provide comprehensive survivorship care
- Identify adult providers as patients leave your care
- Stay educated on current guidelines

PARENTS

- Support your survivor
- Remain a resource
- Encourage independence and knowledge
- Check in with yourself

The Aftershock

- Secondary cancers
- Organ dysfunction
- Impaired cognition
- Psychological problems
- Infertility
- Growth deficiency



Passport for Care

- Free online resource for survivors *and* clinicians
 - Screening Recommendations Generator
 - COG Guidelines for Survivorship Care
 - Survivorship Plan
 - Other general resources

- 45,000 Survivors entered
- 150 User Clinics worldwide



Treatment Summary

Your treatment summary is your cancer treatment history up to the date of the completion of your treatment. It does not contain any subsequent treatments or health changes. The summary is only as complete as the information provided by your Long-term Survivor clinic or treatment clinic. It does not contain a full medical history. This summary is used to generate your long-term follow-up guidelines.

If the cancer treatment history has changed, for example, due to treatment for recurrence of the primary cancer or development/treatment for another type of cancer, it is important to have the treatment record reviewed and updated if required. Please contact the Help Desk at svp-helpdesk@bcm.edu regarding this matter.

Demographic Information

Name: Brady, Thomas

Medical Record Number: 12345678

Date of Birth: April 16, 2010

Treatment Summary, Cont.

Primary Diagnosis

Diagnosis: Leukemia: Acute lymphoblastic leukemia

Date of Diagnosis: August 19, 2017

Age at Diagnosis: 7 years, 4 months

Sites Involved/Stage/Diagnostic Details: BONE MARROW

Heredity/Congenital History: Down syndrome

Present Pertinent History:

Presented to pediatrician after 1 month history of fatigue, leg pain, headaches and mom thought he looked pale. CBC done revealed extremely elevated wbc, low hemoglobin and low platelet count. Referred to Texas Children's Cancer Center. Work up for leukemia completed, diagnosed with CNS negative acute lymphoblastic leukemia, started treatment and went into remission within first 28 days.

Past Medical History: surgery x 2 for ear tubes due to recurrent infections

Treatment Center

Primary Diagnosis: Leukemia: Acute lymphoblastic leukemia

Texas Children's Cancer Center

Treating Physician: Dr.
Gramatges

Medical Record Number:

Current MD/APN Contact:
Alicia Howell PNP

- Diagnosis
- Providers
- Protocol
- Chemotherapy
- Surgery
- Complications
- Late Effects

Information for Your Doctor

Your information on Passport for Care is most helpful when you share it with your doctor. For your convenience, by clicking the buttons below, you can download (as a PDF) or print your Treatment Summary and your Follow-Up Care Plan.

 Download Info For Your Doctor

 Print Info For Your Doctor

Treatment Summary, Cont.

Complications/Late Effects

Primary Diagnosis: Leukemia: Acute lymphoblastic leukemia

Psychosocial: Post-traumatic stress disorder

Onset Date:

Resolved Date:

Status: Active

Cardiovascular: Cardiomyopathy

Onset Date:

Resolved Date:

Status: Active

EF 24% 04-15-2019, followed by TCH cardiology clinic

Endocrine: Hypothyroidism - Primary hypothyroidism (thyroid gland failure)

Onset Date:

Resolved Date:

Status: Active

- Downloadable & printable resource for Survivors

Survivorship Care Plan

Body system potentially affected	You <i>may</i> be at risk for	→ Suggested Screenings
<p>Cardiovascular Heart and blood vessels</p>	<p>Cardiac toxicity Heart problems including weakening of the heart muscle (cardiomyopathy), heart failure, and/or abnormal heart rhythms</p> <p>→ ? Why?</p> <p>Learn more</p> <p>→ Cardiovascular Risk Factors ↗ - View Other Languages</p> <p>Diet and Physical Activity ↗ - View Other Languages</p> <p>Heart Health ↗ - View Other Languages</p>	<p>Yearly; Heart tests at the start of long-term follow-up, and then as recommended based on treatment; Referral to specialist if needed</p> <p>Check-up; Heart tests such as echocardiogram (test to check heart muscle function) and electrocardiogram (test to check heart rate and rhythm); May be referred to a cardiologist (heart specialist)</p>
	<p>Thrombosis; Vascular insufficiency; Infection of retained cuff or line tract; Post-thrombotic syndrome</p> <p>Blood clots, decreased blood flow, or infection at the site of your central line</p> <p>? Why?</p>	<p>Yearly Check-up</p>

Screening Recommendations Generator

Screening Recommendations Generator

Demographics

Sex*

Date of Birth*

Date of Diagnosis*

Radiation

Site

Dose (gy)*

[Delete Radiation](#)

[Add Radiation](#)

Chemotherapies

[Delete Chemotherapy](#)

[Add Chemotherapy](#)

Surgeries

- Free & accessible to everyone
- No sign-in necessary
- COG guidelines

Survivorship Care Plan

Body system potentially affected	You <i>may</i> be at risk for	Suggested Screenings
<p>Cardiovascular Heart and blood vessels</p>	<p>Cardiac toxicity Heart problems including weakening of the heart muscle (cardiomyopathy), heart failure, and/or abnormal heart rhythms</p> <p>? Why?</p> <p>Learn more Cardiovascular Risk Factors - View Other Languages Diet and Physical Activity - View Other Languages Heart Health - View Other Languages</p>	<p>Yearly; Heart tests at the start of long-term follow-up, and then as recommended based on treatment; Referral to specialist if needed Check-up; Heart tests such as echocardiogram (test to check heart muscle function) and electrocardiogram (test to check heart rate and rhythm); May be referred to a cardiologist (heart specialist)</p>
	<p>Thrombosis; Vascular insufficiency; Infection of retained cuff or line tract; Post-thrombotic syndrome Blood clots, decreased blood flow, or infection at the site of your central line</p> <p>? Why?</p>	<p>Yearly Check-up</p>

Next Steps

- Visit our website!
 - passportforcare.org
 - Try out the Screenings Recommendations Generator
- Contact Me!
 - exshohet@texaschildrens.org
 - svp-helpdesk@bcm.edu

Thank You!