ECHO IDAHO

Cancer Survivorship

Beyond the Cancer Center: Navigating Survivorship in Primary Care

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Learning Objectives

- Hear from:
  - Jeffrey Allen, MD (Kootenai Health)
  - Alicia Stoehr, BSN, RN, OCN (St. Luke's Breast Care Services)
  - Amanda Foster, LMSW (Saint Alphonsus Cancer Institute)

- Recognize common psychosocial and quality-of-life concerns experienced by cancer survivors after treatment.
- Identify survivorship resources and support services available throughout Idaho.
- Apply a patient-centered approach that emphasizes connection, assessment, and coordinated support rather than referral alone.

The Evolution of Comprehensive Cancer Care in the U.S.











Late 1800s–1930s

Early Cancer Institutions and Specialization

- Cancer treatment initially focused on surgery; radiation emerged after the discovery of X-rays and radium.
- Dedicated cancer hospitals and clinics established (e.g., Memorial Hospital, New York, 1884).
- Cancer recognized as a distinct medical specialty.

1940s–1960s

Advances in Treatment and Multidisciplinary Care

- Introduction of chemotherapy (e.g., Sidney Farber's leukemia treatments).
- Growing collaboration among surgery, medical oncology, and radiation oncology.
- Clinical trials and research increasingly integrated into patient care.

1971

National Cancer Act

- Major expansion of federal investment in cancer research and care.
- Strengthened the National Cancer Institute (NCI).
- Accelerated development of a national network of cancer centers.
- **1973:** NCI designates eight Comprehensive Cancer Centers.

1980s–1990s

Integrated, Team-Based Cancer Care

- Tumor boards and disease-specific teams become standard.
- Standardized treatment protocols and coordination across specialties.
- Increased recognition of supportive care, hospice, psycho-oncology, and symptom management as part of cancer care.

2000s–Present

Expanding the Scope of Comprehensive Care

- Patient navigation and survivorship programs.
- Genetics, precision medicine, and targeted therapies.
- Earlier integration of palliative care.
- Greater attention to psychosocial support, rehabilitation, and long-term wellbeing.
- Ongoing focus on reducing disparities and improving access to high-quality care.

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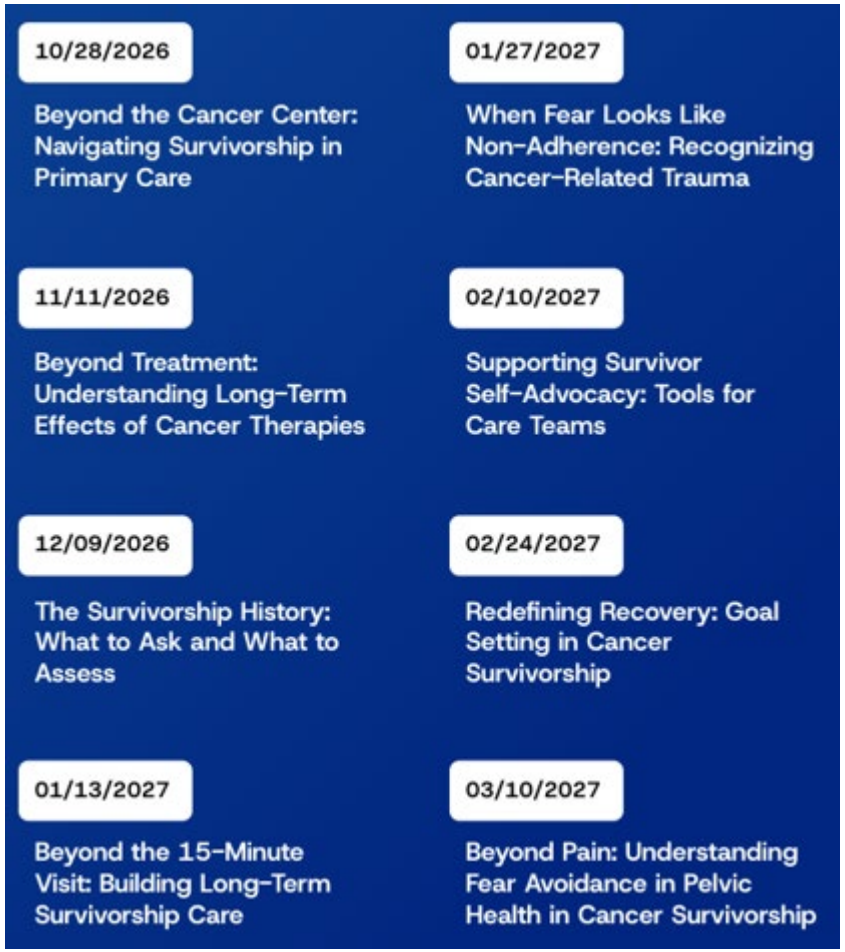
- Board certified in Internal Medicine, Hematology, and Medical Oncology
- Nearly 20 years in clinical practice
  - Academics, private practice, hospital-based practice
- Interest in clinical research.
  - Co-Principal Investigator for the Montana Cancer Consortium (http://www.mtcancer.org)
  - Prior experience as national PI for cooperative group research trial
  - Prior experience conducting phase I clinical trials

Kootenai Health Introduction

- Kootenai Health
  - Based in Coeur d'Alene, ID
  - Founded in 1956 as the Kootenai Hospital District, later converted to a non-profit 501(c)3
  - Licensed for 381 beds
  - > 4,000 employees
  - COC accredited
  - NAPBC accredited
- Kootenai Clinic Cancer Services
  - 3 clinics – Coeur d'Alene, Post Falls, and Sandpoint
  - 4.25 FTE Hem/Onc physicians, 5.25 FTE APPs
  - Over 100 FT employees including providers, nurses, pharmacists, research coordinators, social workers, dieticians, rehabilitation services, etc.
  - Care for full spectrum of solid and liquid tumors including acute leukemias, immunotherapies, and bispecific antibodies
  - Do not offer stem cell transplantation or CAR-T cell therapy (nearest is Fred Hutch in Seattle)

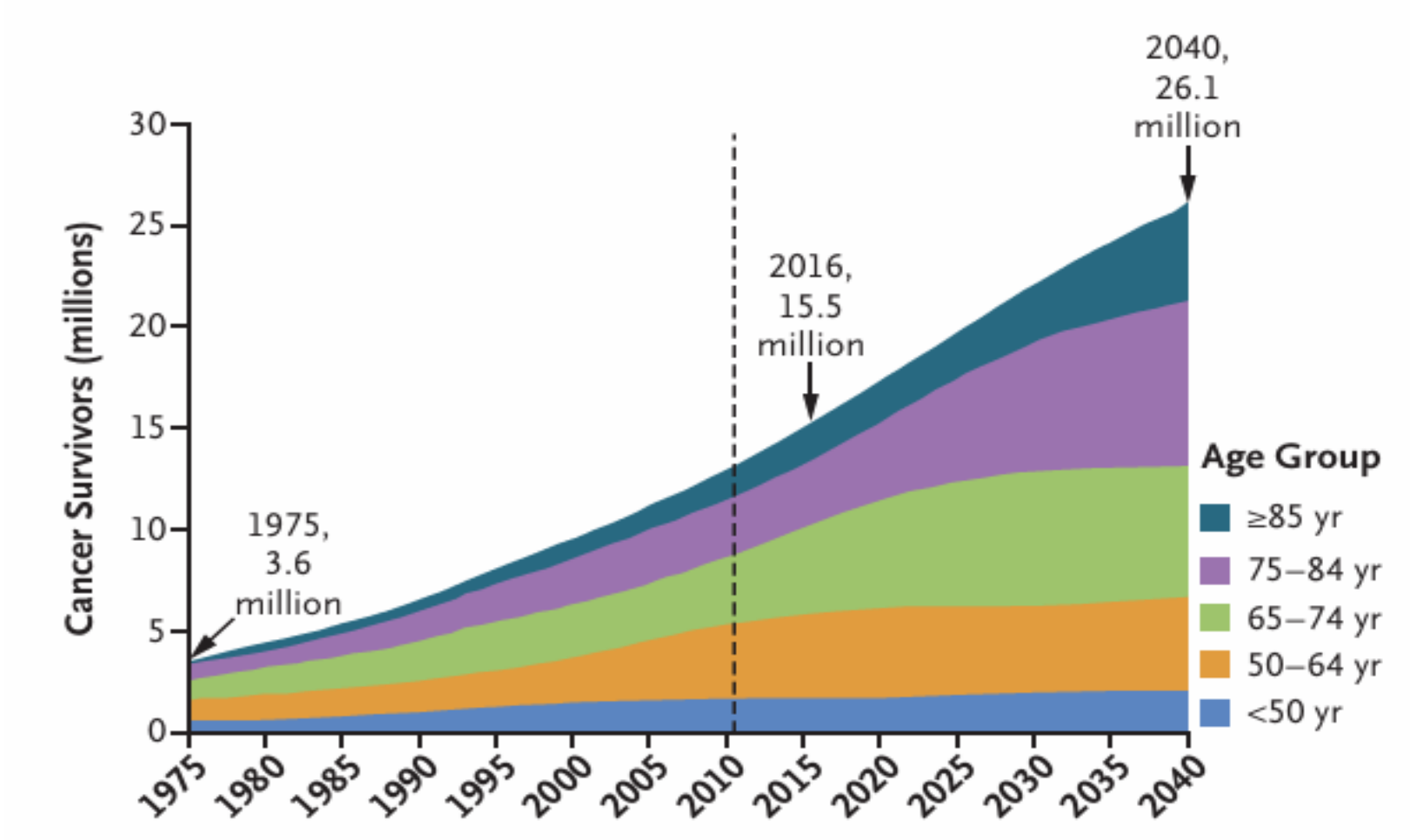
Cancer Survivors

- What does it mean to be a cancer survivor?
  - An individual is considered a cancer survivor from diagnosis, through the balance of life[1].
  - Includes those that might be free from cancer and those who might still be living with cancer.
- How does a cancer diagnosis and cancer treatment affect patients?
  - Physical health
  - Mental health
  - Health and lifestyle behaviors
  - Sexual function/dysfunction
  - Financial health



[1] National Coalition for Cancer Survivorship, https://cancercontrol.cancer.gov/definitions.

Cancer Survivors – The Scope of the Challenge

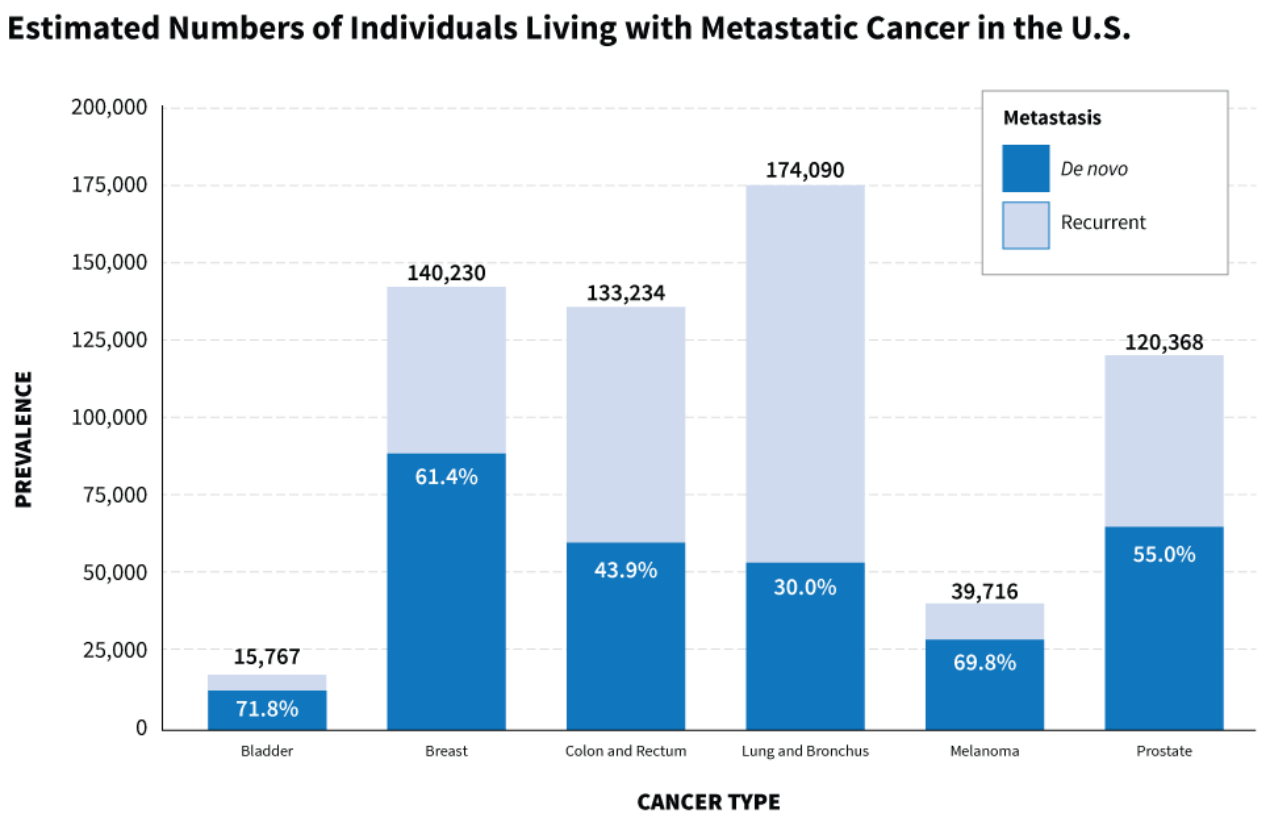


Shapiro CL, Cancer Survivorship, New England Journal of Medicine 2018;379:2348-50.

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Cancer Survivors – The Scope of the Challenge



Estimated numbers of individuals living with metastatic cancer in the U.S. on January 1, 2018, by cancer type, and percentage by cancer type who were diagnosed with metastasis *de novo* versus with early-stage disease that progressed to metastatic disease. Numbers above each bar represent total estimated metastatic prevalence for each cancer type.

Gallicchio L, Devasia TP, Tonorezos E, Mollica MA, Mariotto A, Estimation of the numbers of individuals living with metastatic cancer in the United States, JNCI: Journal of the National Cancer Institute, 2022.

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Goals of Survivorship Care

- Monitoring for recurrence of existing cancer
- Screening for new malignancies
- Preventing/detecting effects of cancer and/or treatment
- Coordination of care
  - It takes a village to care for cancer patients!
- Planning for ongoing survivorship care
- Promoting healthy behaviors

Adapted from the NCCN Guidelines for Survivorship, version 3.2026, https://www.nccn.org.

Models of Survivorship Care

Model	Primary Responsibility	Pros	Cons
In-clinic care	Oncology clinic provides cancer treatment and follow-up care	Patients often prefer specialist care	Insufficient preventive health care
Survivorship clinic	Care provided within specialty practice by providers focused on survivorship care	Efficient model in terms of resource utilization	Difficult to develop; may be limited to large community practices or academic centers
Shared care	PCP and oncologist provide coordinated care	Better communication between oncology team and PCP team	May be difficult for PCP team due to lack of expertise, skills, knowledge of cancer
Multispecialty Clinic	Multiple specialists provide care in the same clinic	May be preferred by patients	Most inefficient model; resource intensive

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Survivorship at Kootenai Health

- Practice varies as to when a patient might be discharged from the cancer center.
  - Variation from provider to provider, disease to disease
- Patients are provided a treatment summary.
- Most often, patients will remain in touch with us at the cancer center, though visit frequency is reduced (shared care model, though often informal).
  - Constant encouragement to have patients see their PCP for non-cancer concerns
- Patients are encouraged to call or message us if they have any concerns or questions.
- Survivorship clinic in the future?

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Treatment Summary

Survivorship Care Plan	
Patient Name:	Patient DOB:
Health Care Providers	
Primary Care:	Phone Number:
Surgeon: KH General Surgery	Phone Number: (208) 625-5200
Medical Oncologist: KCCSMD	Phone Number: KCCSPH
Radiation Oncologist: NWXRTMD	Phone Number: (509) 228-1000
Treatment Summary	
Diagnosis	
Cancer Type: Stage: No matching staging information was found for the patient.	Diagnosis Date:
Treatment Completed	
Treatment Goal: ☐ To cure the cancer and relieve symptoms and side effects of Treatment ☐ To slow the growth of the cancer and relieve symptoms and side effects of treatment	

Surgery: YES/NO	Surgery Date:	Surgical/Findings:
Radiation: YES/NO		
Systemic Therapy (chemotherapy, hormonal therapy, other) YES/NO		
Need for ongoing (adjuvant) treatment for cancer YES/NO		

Schedule of Clinical Visits	
Coordinating Provider	When/How often
KCCSMD	Labs and imaging as indicated by provider
	Annual wellness exam with age-appropriate screening
CCNW XRT MD	Alternating with other providers or as indicated
Cancer surveillance or other recommended related tests	
Coordinating Provider	When/How often
KCCSMD	Labs and imaging as indicated by provider

Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:

- Anything that represents a brand new symptom;
- Anything that represents a persistent symptom;
- Anything you are worried about that might be related to the cancer coming back.

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

Emotional and mental health	Fatigue	Weight Changes
Stopping smoking	Sexual functioning	Fertility
Physical Functioning	Insurance	School/Work
Financial advice or assistance	Parenting	
Memory or concentration loss		

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

Tobacco use/cessation	Diet
Alcohol use	Sunscreen use
Weight management (loss/gain)	Physical activity
Management of medications	Management of other illnesses

Resources you may be interested in:
American Society of Clinical Oncologists: www.cancer.net
National Comprehensive Cancer Network: www.nccn.org
National Coalition for Cancer Survivorship: www.canceradvocacy.org/
National Cancer Institute: www.cancer.gov/cancertopics/coping/survivorship

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Challenges for Survivorship Care at Kootenai Health

- Effectively communicating survivorship care plan
  - In Northern Idaho/Western Montana, many practices remain independent and use varied EHRs
  - Print, fax, scan
- Coordinating care
  - Specialists are often spread across multiple systems/locations
    - Specialty surgery in Spokane, WA
    - Radiation therapy in Coeur d'Alene area
    - Special rehabilitation programs limited to Coeur d'Alene or Spokane region
    - Tertiary oncology care in Seattle, WA
  - Oncology clinics
    - Coeur d'Alene area, Sandpoint
- Access to care
  - Significant turnover within primary care practices in the region
  - Limited bandwidth at specialty clinics (including oncology)

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Breast Care Services

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Supportive Oncology Services at St. Luke's

At St. Luke's, survivorship begins at diagnosis and is supported across the cancer-care continuum.



Supportive Oncology Addresses:

- Physical & functional
- Emotional & spiritual
- Practical & financial
- Symptoms, quality of life & survivorship

No universal time limit applies across supportive oncology services. Eligibility, referral pathways, location, and availability vary by service.

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SUPPORTIVE ONCOLOGY

St. Luke's Cancer Institute

CANCER REHABILITATION

Function, daily activities, cognition, swallowing and lymphedema



NUTRITIONAL COUNSELING

Nutrition and hydration across the cancer continuum



INTEGRATIVE MEDICINE

Acupuncture, massage, yoga and symptom support



PALLIATIVE CARE

Symptom management, care planning and quality of life



PSYCHIATRY

Psychiatric and emotional support related to cancer



SOCIAL WORK

Emotional support, practical needs and community resources



FINANCIAL ADVOCACY

Insurance, financial assistance and barriers to care



SPIRITUAL CARE

Meaning, grief, spiritual concerns and caregiver support



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How Survivorship Has Been Supported at St. Luke's

Historical Clinical Model

- Multidisciplinary post-treatment clinic pilot
- Comprehensive visit for eligible patients
- Not currently operating

Education & Connection

- SHINE survivorship education
- Living Beyond Breast Cancer series
- Special-topic events and recorded resources
- Format and availability have changed

Current Supportive Pathways

- Supportive oncology referrals
- Support groups and specialty clinics
- Treatment summaries and care plans
- Internal and community resources

These approaches met important needs, but they have not always functioned as one visible, consistently staffed survivorship pathway.

What We Learned From St. Luke's Survivorship Programs

What Patients Valued	What Affected Sustainability
• Practical, understandable education • Earlier access to survivorship information • Virtual participation options • Local and national resources • Connection with others	• Program operations concentrated in one role • Reliance on volunteer speakers • Outreach and registration demands • Scheduling and technology barriers • Staffing transitions and competing clinical needs

Valuable programming still requires shared ownership, staffing, and a continuity plan.

Access and Transition at St. Luke's

Established Pathways	Areas of Variation
• Medical or radiation oncology referral pathways • Some services available by referral or patient request • Social work and spiritual care through distress screening • Care plans by request for eligible curative-intent patients	• Surgery-only patients may not automatically enter the same pathway • There is no single survivorship entry point • Availability varies by service, location, and capacity • Oncology-to-primary care transition is not standardized through one universal pathway

No universal time limit applies to supportive oncology services, but access remains service-specific.

Extending Survivorship Support Into the Community

Rehabilitation and Wellness	• YMCA Oncology Recovery Program
Reproductive Health	• Idaho Center For Reproductive Medicine
Peer and Caregiver Support	• St. Luke's and Community Support Groups • Disease-specific and Caregiver Programs
Practical and Rural Resources	• Transportation and Financial Assistance • Idaho 211 and Findhelpidaho.Org • Statewide and National Virtual Resources

Community partnerships expand the network when Cancer Institute services are limited by eligibility, geography, capacity, or fit.

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St. Luke's Survivorship: Strengths & Opportunities

STRONG FOUNDATION	OPPORTUNITIES
• Broad multidisciplinary supportive oncology network • Programs and services across the cancer continuum • Community partnerships that extend support • Ongoing program evaluation and development	• A clearer survivorship entry point • More consistent access across treatment pathways and locations • Clearer transition among oncology, primary care, and community resources • Sustainable ownership across roles and staffing changes

The next opportunity is to help survivors experience these resources as one connected pathway rather than as separate services.

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The Survivorship Transition

The Survivorship Paradox

- What patients expect after cancer:
  - Treatment ends → Life returns to normal → They move forward with life
- What often happens:
  - Fear of recurrence
  - Anxiety and Depression
  - Fatigue
  - Cognitive changes
  - Isolation
  - Relationship changes
  - Uncertainty about the future

The Questions Behind the Questions

A survivor may say:

"I'm tired."

What they may really mean:

- I can't work like I used to.
- I can't keep up with my family.
- I'm scared something is wrong.
- I don't recognize myself anymore.

A survivor may say:

"I'm doing okay."

While still experiencing:

- Fear of recurrence
- Depression
- Financial concerns
- Relationship strain
- Social isolation

A Referral is Not Enough

Before asking:
"Who should I refer you to?"

Consider asking:

- What has been the hardest part since treatment ended?
- How is this affecting your day-to-day life?
- What concern keeps you up at night?
- What support do you feel you're missing?

Why It Matters
Understanding impact helps identify the right intervention the FIRST time

What Can Realistically Be Managed in Primary Care?

You don't have to manage every survivorship issue yourself. Your role is often identifying concerns, supporting engagement in care, and helping connect survivors to the appropriate resources.

- ✓ Screen for distress and survivorship concerns[123]
- ✓ Normalize common survivorship experiences[124]
- ✓ Support chronic disease management[123]
- ✓ Monitor quality-of-life concerns[12]
- ✓ Encourage healthy lifestyle behaviors and wellness strategies[12]
- ✓ Identify when additional specialty support is needed[123]
- ✓ Coordinate care between oncology and community providers[123]
- ✓ Encourage adherence with recommended surveillance imaging and follow-up[123]
- ✓ Address scan-related anxiety and anticipatory distress, including consideration of PRN medications when clinically appropriate[12]
- ✓ Help ensure labs and surveillance testing are completed at appropriate intervals to reduce the risk of patients being lost to follow-up[123]

Survivorship is a Team Sport

Support may include:

- Primary Care
- Oncology
- Oncology Social Work
- Registered Dietitians
- Genetic Counselors
- Speech Language Pathologists
- Rehabilitation Therapies
- Community Organizations
- Peer Support Programs[123]

Patients often spend months or years surrounded by a multidisciplinary team. Then treatment ends and they feel disconnected from that support.

Many resources remain available long after treatment is complete.

When Geography Creates Barriers

Common Challenges

- Long travel distances
- Transportation barriers
- Limited specialty services
- Workforce shortages
- Isolation
- Financial limitations[123]

Strategies That Help

- Telehealth
- Virtual support groups
- Community partnerships
- Shared care models
- Ongoing communication with oncology[123]

Key Takeaway: Distance should not determine access to survivorship support.[123]

Survivorship Resource Toolkit

Idaho Based Support:

- **Idaho Society of Clinical Oncology (ISCO)**
  - Statewide oncology collaboration, education, and advocacy.
- **Comprehensive Cancer Alliance for Idaho (CCAI)**
  - Statewide cancer education, partnerships, survivorship resources, and advocacy.
- **Bustin' Out of Boise**
  - Support, wellness programs, and connection opportunities for women impacted by cancer.
- **Idaho2Fly**
  - Programming and support focused on men impacted by cancer.

FindHelp.org – for more Rural Resources

Connects individuals with:

- Financial assistance
- Housing resources
- Transportation support
- Food assistance
- Community programs

Your Local Oncology Social Worker – Call a center and ask!

May assist with:

- Emotional support
- Resource navigation
- Financial resources
- Support group referrals
- Community resource coordination[1235]

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Saint Alphonsus
Nourish & Flourish Survivorship Program

Saint Alphonsus
A Member of Trinity Health

Co-Facilitated By

- Amanda Foster, LMSW, OSW-C
- Ellie Leckenby, RDN

Group Components:

- Psychosocial support
- Nutrition education
- Cooking demonstrations
- Peer connection
- Survivorship education[124]

Open To:

- Anyone diagnosed with cancer
- Idaho and Oregon residents
- Virtual attendance available via teams
- **NOT** limited to Saint Alphonsus patients



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Why Connection Matters

Research and patient experience consistently tell us survivors need:

- **Information**
  - "What should I expect from survivorship?"
- **Validation**
  - "Is what I'm feeling normal?" or "Is this forever?"
- **Connection**
  - "Am I alone in this?"
- **Support**
  - "What do I do next?"[1245]

Conclusion

- **Survivorship care goes beyond surveillance**
  - Often requiring ongoing attention to physical, emotional, and psychosocial needs
- **Referrals alone are not enough**
  - Meaningful conversations and strong connections help identify and address survivors' real challenges
- **Survivorship is a team effort**
  - Patients benefit most when primary care, oncology, social services, and community resources continue working together

Questions and Discussion

References

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