Your Journey on the Survivorship Highway

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Objectives

• Describe what you might expect *along the road* after cancer treatment is completed.

• Have increased awareness of *common hazards* – the long term and late effects of cancer and cancer therapies.

• How you can *be in the driver’s seat* on your survivorship journey.
What to expect...
Who are Survivors?

“...anyone who has been diagnosed with cancer from the time of diagnosis through the balance of his or her life”

What is Survivorship?

Dealing with the unique needs of survivors after active treatment ends
Difference Between Late and Long Term Effects

- **Long Term Effects**
  Effects or complications during treatment that can continue into the future
  Example – fatigue, sexual problems, worry

- **Late Effects**
  Effects from treatment that may not show up for months or years after treatment ends
  Example – secondary cancers, heart disease
HOW CANCER HAS AFFECTED POST-TREATMENT SURVIVORS: A LIVESTRONG REPORT
FINAL REPORT
Percentage of Respondents who report physical concerns

- Energy (N = 1,356): 59%
- Concentration (N = 1,261): 55%
- Neuropathy (N = 1,058): 46%
- Pain (N = 780): 42%
- Lymphedema (N = 527): 34%
- Incontinence (N = 503): 23%
- Oral health (N = 458): 22%
- Lungs (N = 362): 20%
- Vision (N = 298): 16%
- Thyroid (N = 207): 13%
- Hearing (N = 183): 9%
- Heart (N = 184): 8%
- Infertility (N = 138): 8%
- Graft-versus-host (N = 1): 3%
- Others (N = 1): 1%
Lack of care: Percentage of respondents who did not receive help for their concerns

- Graft-versus-host (N = 0): 0%
- Thyroid (N = 23): 11%
- Oral health (N = 105): 23%
- Heart (N = 59): 32%
- Lymphedema (N = 174): 33%
- Hearing (N = 68): 37%
- Vision (N = 110): 37%
- Pain (N = 289): 37%
- Lungs (N = 173): 47%
- Infertility (N = 69): 50%
- Energy (N = 759): 56%
- Neuropathy (N = 578): 60%
- Incontinence (N = 347): 69%
- Sexual functioning (N = 751): 71%
- Concentration (N = 1,047): 83%
Percentage of respondents who experienced emotional concerns

- Fear of recurrence (N = 1,927): 80%
- Grief and identity (N = 1,563): 68%
- Personal appearance (N = 1,426): 62%
- Family member risk (N = 1,714): 51%
- Sadness and depression (N = 1,169): 51%
- Personal relationships (N = 709): 31%
- Social relationships (N = 666): 29%
- Faith and spirituality (N = 183): 8%
Lack of care: percentage of respondents who did not receive help for their emotional concerns

- Sadness and depression (N = 689): 59%
- Fear of recurrence (N = 1,206): 66%
- Personal appearance (N = 955): 67%
- Family member risk (N = 822): 70%
- Grief and identity (N = 1,172): 75%
- Personal relationships (N = 539): 76%
- Social relationships (N = 506): 76%
- Faith and spirituality (N = 146): 80%
Case Study: Colorectal Cancer

• 46 year old man diagnosed with Stage IIC rectal cancer.

• Treatment included
  – Urgent surgery
  – Ostomy - potentially reversible
  – Prolonged recovery due to infection
  – Chemotherapy
  – Radiation
What might be expected?

BUMP

SLOW
Potential Long Term and Late Effects
Chemotherapy & Biotherapy

- Chronic Fatigue
- Cardiovascular disease
- Lung toxicity
- Infertility
- Metabolic syndrome – insulin resistance, hyperlipidemia, hypertension.
- Cognitive dysfunction – “Chemobrain”.
- GI toxicity
- Dental impairments

- Peripheral neuropathy
- Kidney dysfunction
- Bladder dysfunction
- Liver dysfunction
- Second malignancy – leukemia, skin cancers, breast cancer
- Hearing loss/tinnitus
- Late effects of corticosteroids – bone loss, avascular necrosis, cataracts, myopathy.
- Unknown effects of newer agents?
And More Potential Long Term and Late Effects...

- **Surgery**
  - Organ dysfunction or loss
  - Scarring or fibrosis, adhesions
  - Lymphedema
  - Change in Body Image
  - Infection

- **Radiation**
  - Organ dysfunction within radiation field:
    - Thyroid, brain, kidney, liver, lung, bone, intestines, ovaries, testes.
  - Skin fibrosis
  - Second malignancy
  - Cognitive changes with brain radiation.
What Can Effect Your Risk?

- Age
- Gender
- Genetics
- Social
- Other Health
- Lifestyle

- Radiation
- Chemotherapy
- Surgery
Back to our Case Study: Colorectal Cancer

• 46 year old man diagnosed with Stage IIC rectal cancer.
• Healthy before cancer
• Healthy family history
• Supportive wife and kids
• Supportive job
• Non-smoker
• Not much exercise
• Overweight
Rough Roadway –
Long Term and Late Effects

- Fatigue
- Role in family
- Financial worries
- Return to work
- Logistics of treatment, recovery time, work coordination
- Intimacy and sexuality
- Fear of recurrence
- Surgery for ostomy reversal planned

- Potential for:
- Scar tissue/adhesions
- Skin and nail changes
- Change in bowel function
- Nutrition issues
- Neuropathy
- Bone density in radiation field
- Sexual function
- Second cancers
- Fear of recurrence
Let’s Look at two long term effects: Fatigue and Intimacy

• Fatigue is the most common physical symptom across diseases after chemotherapy or radiation.

• For some it continues for years.

• Fatigue and depression are not the same, but they can be hard to tell apart and they are related.
What is Cancer-Related Fatigue?

National Comprehensive Cancer Network Definition, 2010:

“A distressing persistent, subjective sense of **physical**, **emotional** and/or **cognitive** tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.”

✓ 20-50% of cancer survivors

✓ In survivors fatigue includes lack of stamina or energy, muscle loss and related weakness
Exercise Can Help Many Late Effects

- 44 randomized controlled trials
- Weight resistance training

**IMPROVES:**
- Muscle mass, strength, endurance, flexibility
- Insulin-like growth factor-I (IGF-1)
- Cardiopulmonary health, aerobic fitness
- Bone density, reducing fracture risk
- Sleep
- Positive mood
- Self-esteem
- Overall quality of life

*Brown et al. Cancer Epi Biomarkers Prev, 2011 (review)*
*Fong et al. BMJ, 2012 (review)*
Time, Talking, and Trying Things Works, too!

- Intimacy and sexuality
  - Talking, asking questions
  - Going slow
  - No expectations
  - A sense of humor helps
  - Books, resources, assistive devices
  - Ask for education or help if something is more difficult than it should be
Case Study: Breast Cancer

• 53 year old woman diagnosed with Stage III, ER /PR positive, Her2neu positive, left breast cancer.

• Treatment included
  – neo-adjuvant chemotherapy
  – mastectomy
  – Herceptin
  – radiation to chest wall and axillary lymph nodes
  – Planned: 5 years of aromatase inhibitors
Dangerous Curves:
Long Term and Late Effects

• Heart/cardiac risk
  – Treatment related
  – Personal or Family history?
• Lung/pulmonary risk
• Lymphedema
• Body Image changes
• Intimacy and sexuality
• Bone health
• Fatigue

• Genetic risks
• Second cancers
• Fear of recurrence
• Muscle and joint aches and pain
• Menopausal symptoms
• Sleep disturbances
• Anxiety and depression
• Social isolation
• Changes in memory and brain processing speed
Let’s look at three potential effects

- Distress
- Memory
- Bone Health
Distress Reactions of Survivors

Uncertainty
- Not knowing what the future will bring
- Thoughts and feelings about recurrence

Grief and Loss
- What will never be (fertility/pregnancy)
- What is changed forever (hair, work, energy)
- Includes body image, self-esteem

Fear of Recurrence
- Intrusive thoughts about cancer recurring
- Worry encroaches on activities, sleep, enjoyment
- Afraid to rebuild life - disappointment
In the Words of a Non-Hodgkin's Survivor

“After I was in remission a few years, I was told to call my doctor if I had a problem. But after cancer, you starting imagining the worst with every little twinge: is this something I should watch for or be concerned about?”
“Someone likened cancer to a pink elephant, and the pink elephant initially is right there in front of your face, you know... and then as you get better, the pink elephant maybe goes to another room. And then as you get much better, the pink elephant goes down the street, but it’s always there and you always know it’s there.”

Common cognitive complaints among adult cancer survivors

- Memory acquisition and retrieval
- Sustained attention, screening out distractions
- Speed of information processing
- Multi-tasking
- Executive functions
- Planning and organizing
  - Trial and error reasoning
  - Complex attention
Treatment of Memory and Attention

- Medical evaluation including hormone/endocrine and medication review
- Psychological evaluation and treatment
  - Counseling, support groups, behavioral therapy
- Neuropsychological evaluation
- Pharmacologic treatment may help some people
  - For anxiety, depression, or attention
- Cognitive rehabilitation / adaptation strategies
But, it is not all bad news!
Post-Traumatic Growth & Benefit Finding

• Perceived changes in self:
  – Feeling stronger
  – More self assured
  – More experienced
  – More able to face future challenges
Bone Health – Assess and Address

• Osteopenia and osteoporosis
  – Risks: radiation, chemotherapy, post-treatment medications
  – Testing: DEXA scans
  – Treatment:
    • Prevention – diet, calcium, vitamin D, resistance exercise
    • Physical Therapy
    • Prescription medications
Prevention Works!

Control the things you can control...

• We can minimize road hazards by driving a safe vehicle!
• Keep blood pressure, cholesterol, blood sugar and weight under control
  – Nutrition is vital
  – Exercise
  – Addressing emotional needs
  – Manage stress
  – Alcohol and substance use
  – Quit smoking
  – Sleep is critical for physical and emotional well-being, immune function, and coping
Patient: Doctor, I don't feel well and I'm not sure why.

Doctor: I want you to meditate for 20 minutes, twice a day, exercise for at least 30 minutes a day, avoid processed foods, eat plenty of organic fruit and veg, spend more time in nature and less indoors, stop worrying about things you can't control and ditch your T.V. Come back in 3 weeks.
Survivors Quality of Life Issues Can Be Multiple and Complex

Medical Problems:
- ✓ Cardiovascular disease and cardiac failure
- ✓ Fatigue
- ✓ Osteoporosis / osteopenia
- ✓ Hypothyroidism
- ✓ Premature menopause
- ✓ Pulmonary function
- ✓ Lymphedema
- ✓ Urinary incontinence
- ✓ Infertility
- ✓ Neurologic problems (balance, neuropathy, memory)
- ✓ GI (bowels, bloating, acid reflux)
- ✓ Dental impairments
- ✓ Recurrence/Increased risk of 2nd cancers
- ✓ Accelerated aging

Emotional and Functional Concerns:
- ✓ Restricted social and physical activities
- ✓ Memory loss
- ✓ Fear of recurrence/living with uncertainty
- ✓ Muscle and joint stiffness, weakness, cramps or pain
- ✓ Sexual dysfunction
- ✓ Intimacy/relationship issues
- ✓ Distress and worry
- ✓ Job loss/Job lock
- ✓ Role changes at home
- ✓ School concerns
- ✓ Insurance problems
- ✓ Financial concern or crisis
- ✓ Sleep disorders
Survivors Lost in Transition
from cancer patient to survivor

• Many survivors don’t necessarily know what they need
  – Unaware of what tests and follow up visits they should have or which physician specialists they should continue to see

• Care Coordination is unclear
  – Oncologist may think primary care is doing prevention
  – Primary care may think oncologist is doing prevention
  – Patient may not know who to see when and for what

• Lack access to survivorship care
  – Services are not available in their community
  – Survivors not able to take advantage of service due to practical constraints (e.g. lack of insurance, lack of transportation, disability)
FHCRC Survivorship Program
SCCA Survivorship Clinic 206-288-1021

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Emy Jensen, Project Coordinator
Joli Bartell, Project Coordinator
Sheri Ballard, Research Assistant
Kelly Ambrose, Project Manager
Goals of a Survivorship Care Plan

• Increase survivors own knowledge of their diagnosis and the treatment they have received and potential consequences of that treatment
• Promote a healthy lifestyle
• Inform survivor of recommended surveillance practices for new or recurrent cancers, other health concerns
• Facilitate transition back to , and inform, primary care providers
1. TREATMENT SUMMARY
## Systemic Therapy (Chemotherapy, Biotherapy, Adjuvant Therapy, Other)

<table>
<thead>
<tr>
<th>Agent:</th>
<th>Route:</th>
<th>Cycles:</th>
<th>Date Start:</th>
<th>Date Stop:</th>
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<tbody>
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### Cumulative Anthracycline Dose Administered:

<table>
<thead>
<tr>
<th>Blood Products:</th>
<th>Growth Factors:</th>
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</table>

### Radiation Therapy

<table>
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<tr>
<th>Date Start</th>
<th>Date Stop</th>
<th>Total Dose (cGy)</th>
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### Fields included:

### Complications of therapy:

<table>
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<tr>
<th>Dose reduction:</th>
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<table>
<thead>
<tr>
<th>Complications (from which modality if known):</th>
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</table>

## Providers

<table>
<thead>
<tr>
<th>General Medical Care:</th>
<th>Oncologic Care:</th>
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<tr>
<td></td>
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<tr>
<td>Long term effects and Follow-Up care</td>
<td>Recommendation</td>
</tr>
<tr>
<td>--------------------------------------</td>
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</tr>
<tr>
<td>Cardiac Health</td>
<td>Heart problems can occur after certain chemotherapy drugs (anthracyclines) or after chest radiation based on the doses you have received.</td>
</tr>
<tr>
<td>Lung/Respiratory</td>
<td>Chemotherapy and radiation may impact lung function. If you are experiencing shortness of breath, chronic cough, pain with breathing, wheezing, increased fatigue or…</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>Muscle and joint aches, stiffness and pain are common after cancer treatment. Narcotics generally do not address the underlying cause. Regular exercise both aerobic and resistance training, stretching, and yoga…</td>
</tr>
<tr>
<td>Cognitive/Memory concerns</td>
<td>It is common after chemotherapy to experience some changes in memory and cognition, frequently referred to as “chemo brain”. Most often these affects improve over the first year after therapy is complete; however…</td>
</tr>
<tr>
<td>Fertility</td>
<td>Chemotherapy and radiation can affect your fertility. It is important to know your fertility status. Women should keep track of menstrual cycles and report any changes…</td>
</tr>
<tr>
<td>Hormonal Changes</td>
<td>Treatment of your cancer may cause hormone changes which can lead to hot flashes, vaginal dryness, mood fluctuations, fatigue, menstrual irregularities, bone density issues, and memory changes.…</td>
</tr>
<tr>
<td>Secondary cancers</td>
<td>There is a low risk for leukemia or other secondary cancers related to chemotherapy and/or radiation exposure. Notify your health care provider…</td>
</tr>
</tbody>
</table>

**Recommendations driven by:**

- Specific Exposure:  
  - Chemo (type/dose)  
  - Radiation (site/dose)  
  - Surgery
- Modified by:  
  - Diagnosis  
  - Age  
  - Gender  

2. CARE PLAN
<table>
<thead>
<tr>
<th>WELLNESS Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Coordination of Care/Health Maintenance</strong></td>
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<tr>
<td><strong>Emotional Health</strong></td>
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<tr>
<td><strong>Intimacy/Sexual Health</strong></td>
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<tr>
<td><strong>Nutrition</strong></td>
</tr>
<tr>
<td><strong>Body Image</strong></td>
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<tr>
<td><strong>Genetics</strong></td>
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<tr>
<td><strong>Exercise/Physical Activity</strong></td>
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<tr>
<td><strong>Sleep</strong></td>
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</tbody>
</table>
# FOLLOW-UP CARE
(to be filled in relevant for each patient)

<table>
<thead>
<tr>
<th>TEST</th>
<th>LAST DONE</th>
<th>FREQUENCY</th>
<th>PROVIDER TO CONTACT</th>
<th>NEXT DUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete Physical Exam</td>
<td></td>
<td>Yearly</td>
<td></td>
<td></td>
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<tr>
<td>Oncology Follow-up</td>
<td></td>
<td>As per oncologist</td>
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<tr>
<td>Surveillance for Risk of Recurrence</td>
<td></td>
<td>Set by your Oncologist</td>
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<tr>
<td>Bone Density Test (DEXA)</td>
<td></td>
<td>Every 2-5 years</td>
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<tr>
<td>Colonoscopy</td>
<td></td>
<td>Every 10 years</td>
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<tr>
<td>Screening Labs, Lipids, etc</td>
<td></td>
<td>Every 1-2 years</td>
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<tr>
<td>Gynecological Exam</td>
<td></td>
<td>Yearly</td>
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<tr>
<td>Pap Smear</td>
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<td>Every 3 years</td>
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<tr>
<td>Mammogram</td>
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<td>Every 2 years</td>
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<tr>
<td>Breast MRI</td>
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<tr>
<td>Skin Exam</td>
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<td>Yearly</td>
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<tr>
<td>Cardiac Screening</td>
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<td>TBD</td>
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<tr>
<td>Vision Exam</td>
<td></td>
<td>Yearly</td>
<td></td>
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<tr>
<td>Dental Exam</td>
<td></td>
<td>Twice a year</td>
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<tr>
<td>Immunizations</td>
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<td>Yearly</td>
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**CONTACT/RESOURCES**
We can’t always choose our road...
...but we all choose our path.
Thank you – Time for Questions