Welcome

UCCLA-LIVE STRONG™ Survivorship Center of Excellence
Third Annual Survivor Education Day

Patricia A. Ganz, M.D.
April 4, 2009
Thank You to Our Supporters

Healthy Lives After Cancer Gift in Memory of Ann Fitzpatrick Alper
Overview of the Day

• Morning activities
  – Plenary lectures
  – Question & Answer Panel
• Lunch on the terrace with speakers
• Afternoon Breakout Sessions-choose 1 in each group (45 minute sessions)
  – Group 1: young adult and childhood survivors; male genitourinary cancers; techniques for coping with cancer; employment/legal issues; cognitive issues after cancer
  – Group 2: hematologic cancer survivors; cancer as a chronic disease; integrative medicine/supplements; physical activity workshop
Cancer Survivorship: a new challenge in delivering quality cancer care

Patricia A. Ganz, M.D
UCLA Schools of Medicine & Public Health
Jonsson Comprehensive Cancer Center
Who are the Cancer Survivors?

- More than 1 in 3 Americans will be diagnosed with cancer in their lifetime
- 11.1 million Americans have a personal history of cancer; 3.6% of US population
- The number of cancer survivors will increase sharply during the next 25 yrs with aging of the population
IOM Findings: Survivorship Care

- Survivorship care is a neglected phase of the cancer care trajectory
- Cancer recurrence, second cancers, and treatment late effects concern survivors
- Few guidelines on follow-up care
- Providers lack
IOM Findings: Survivorship Care

- Survivors may:
  - be unaware of risk
  - have no plan for follow-up
- Opportunities to intervene may be missed
- Cancer care is often not coordinated
- Models of
IOM Findings: Survivorship Care

- Chronic care model applies
- Essential care components
  - Prevention
  - Surveillance
  - Intervention
  - Coordination
Why is cancer different from other chronic diseases?

- Cancer treatment is....
  - Complex
  - Multi-modal
  - Multi-disciplinary
  - Toxic
  - Expensive
  - And often poorly coordinated

- Cancer treatment usually occurs in isolation from primary health care delivery
Why does cancer care present such a challenge?

• An average of 3 specialists/patient, with treatments across time and space…outpatient, inpatient, specialized treatment facilities…. limited communication among treating physicians, multiple medical records
Other Challenges

- Limited systematic study of the late effects of cancer therapy
- Follow-up care plans have been *ad hoc*, with focus on surveillance for recurrence
- When should health promotion and chronic disease prevention become the focus?
Proposed Strategies to Address these Challenges

• Integrated, electronic medical records
• Patient navigators
• Consultation planning

None of these strategies are widely available for patients receiving active treatment!

What happens when treatment ends?
Why do we need a survivorship care plan?

• To summarize and communicate what transpired during cancer treatment.
• To describe known and potential late effects of cancer treatments, with expected time course.
• To communicate to the survivor and other health care providers *what has been done* and *what needs to be done* in the future.
• To promote a healthy lifestyle to prevent recurrence and reduce the risk of other comorbid conditions.
Survivorship Care Plan flows from other IOM Recommendations

- Continuous healing relationships
- Customization based on needs and values
- Patient as the source of control
- Shared knowledge and free flow of information
- Evidence-based decision making
- Safety as a system property
- Need for transparency
- Anticipation of needs
- Decrease in waste
- Cooperation among physicians
Key Elements Included in Survivorship Care Plan

- Specific tissue diagnosis and stage
- Initial treatment plan and dates of treatment
- Toxicities during treatment
- Expected short- and long-term effects of RX
- Late toxicity monitoring needed
- Surveillance for recurrence or second cancer
- Who will take responsibility for survivorship care
- Psychosocial and vocational needs
- Recommended preventive behaviors/interventions
Where does the Survivorship Care Plan fit in the Chronic Care Model?

What are the barriers to routine generation of a treatment summary and survivorship care plan?

• An expectation in some specialties and not others (e.g. radiation therapy vs. medical oncology)
• Lack of appreciation of the need and value added
• Lack of time/reimbursement
• Lack of awareness that survivors and primary care physicians need improved communication
ASCO’s Efforts

- 2006- Pilot versions of treatment summary and care plans in QOPI practices
- 2006-2007: Development of a colon cancer adjuvant therapy template
  - 2 pages in length, including treatment plan and summary
  - ASCO colon cancer surveillance guideline attached
  - Posted on ASCO website with multiple formats
  - Incorporated into EHR vendor products

www.asco.org/treatmentsummary
# Colon Cancer Adjuvant Therapy Treatment Plan & Summary

The Treatment Plan and Summary provide a brief record of major aspects of colon cancer adjuvant chemotherapy. This is not a complete patient history or comprehensive record of intended therapies.

<table>
<thead>
<tr>
<th>Provider name:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient name:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient DOB:</td>
<td>Age at diagnosis:</td>
<td>Patient ID:</td>
</tr>
<tr>
<td>(<em><strong>/</strong></em>/___)</td>
<td></td>
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<table>
<thead>
<tr>
<th>Support contact name:</th>
<th>Support contact relationship:</th>
<th>Support contact phone:</th>
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<tr>
<td></td>
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<table>
<thead>
<tr>
<th>Cancer detection:</th>
<th>Site in colon:</th>
<th>Predisposing conditions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Screening □ Symptoms □ Incidental</td>
<td>□ Right □ Transverse □ Left □ Sigmoid</td>
<td>□ None □ Inflammatory bowel disease □ FAP □ HNPCC</td>
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<table>
<thead>
<tr>
<th>Family history:</th>
<th>Pre-op colonoscopy to cecum:</th>
<th>Other lesions:</th>
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</thead>
<tbody>
<tr>
<td>□ None □ 2nd degree relative □ 1st degree relative □ Multiple relatives</td>
<td>□ Yes □ No</td>
<td>□ None □ Low risk polyps □ High risk polyps</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Primary colon operation:</th>
<th>Date of surgery: (<em><strong>/</strong></em>/___)</th>
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<thead>
<tr>
<th>Surgery type:</th>
<th>CEA pre-op:</th>
<th>CEA post-op:</th>
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<tbody>
<tr>
<td>□ Elective □ Emergent</td>
<td></td>
<td></td>
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<thead>
<tr>
<th>Stage:</th>
<th>T stage:</th>
<th>N stage:</th>
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<tbody>
<tr>
<td>□ IIA □ IIB □ IIIA □ IIIB □ IIIC</td>
<td>□ T1 □ T2 □ T3 □ T4</td>
<td>□ N0 □ N1 □ N2</td>
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<table>
<thead>
<tr>
<th>Number of lymph nodes removed:</th>
<th>Number of lymph nodes positive:</th>
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| Notable pathology findings: | |
|------------------------------| |
| | |
### White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy

<table>
<thead>
<tr>
<th>Height:</th>
<th>Pre-treatment weight:</th>
<th>Post-treatment weight:</th>
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<tbody>
<tr>
<td>in/cm</td>
<td>lb/kg</td>
<td>lb/kg</td>
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**Pre-treatment BSA:**

**Name of regimen:**

**Treatment on clinical trial:** □ Yes □ No

**Start Date:** (____/____/____)  **End Date:** (____/____/____)

<table>
<thead>
<tr>
<th>Bio/Chemotherapy Drug Name</th>
<th>Route</th>
<th>Dose</th>
<th>Schedule</th>
<th>Dose reduction needed</th>
<th>Number of cycles administered</th>
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<tr>
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<td></td>
<td>□ Yes____% □ No</td>
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<td>□ Yes____% □ No</td>
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<td>□ Yes____% □ No</td>
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**Possible side effects of this regimen:**
- □ Hair loss
- □ Neuropathy
- □ Low blood count
- □ Fatigue
- □ Diarrhea
- □ Dehydration
- □ Nausea/Vomiting
- □ Other:

**Number of cycles containing oxaliplatin:**

**Serious toxicities during treatment (list all):**

**Hospitalization for toxicity during treatment:** □ Yes □ No

**Reason for stopping adjuvant treatment:**

**Disease status at end of treatment:** □ No evidence of disease □ Recurrence □ Possible recurrence
ASCO’s Efforts

• 2007-2008: Adjuvant breast cancer treatment plan and summary developed
  – Iterative process; review by breast cancer experts and members of clinical practice committee
  – Final review and approval by the Quality of Care Committee
  – Formal process for further template development instituted

• 2008: Generic chemotherapy template
Journey Forward: Survivorship Care Plan Initiative

A collaboration with:
WellPoint
UCLA Cancer Survivorship Center
National Coalition for Cancer Survivorship (NCCS)
Genentech
• Survivorship Care Plan Builder
  – Free, downloadable tool
  – To be used by oncologists
  – To create custom, post-treatment care plans for cancer survivors in 5 quick steps
**Step 1:** Enter general contact info

- Care plan prepared by: Tiffany Devitt
- Care plan prepared on: 09/04/2009
- Patient name: Jane Doe
- Patient ID: #123165
- Patient phone: 707-555-1211
- Age at diagnosis: 45
- Date of birth: 08/10/1963

**Step 2:** Enter diagnosis & background info

- Affected breast(s): Bilateral
- Definitive breast surgery date: 06/08/2008
- Breast surgery type: Mastectomy
- Sentinel node biopsy: Yes
- Axillary dissection: Yes
- If lymph nodes removed: 2
- Pathological stage: 2
- Genetic testing: Ordered

Additional comments: No notable surgical findings.
Step 3: Describe treatment plan

Step 4: Summarize actual treatment
Step 5: Set follow-up care

Further customize your patient’s survivorship care plan with:
— Guidelines for follow-up care and testing
— A list of symptoms to watch for
— Info on potential late effects of treatment
— A directory of support resources
The Survivorship Care Plan can be printed, saved, edited or emailed.
UC LA-LIVESTRONG™ Survivorship Center of Excellence: Testing Models of Survivorship Care
UC LA-LIVE STRONG™ Survivorship Center of Excellence

- LAF funding facilitates development and coordination of translational clinical programs that will improve survivorship care
  - At UCLA Medical Center
  - Among our community collaborators
  - In the community and region at-large

- Our focus is the development/evaluation of diverse models of cancer survivorship health care delivery
Health Care Partners Medical Group

- San Fernando Valley
- Pasadena / San Gabriel Valley
- Los Angeles
- South Bay
- Long Beach
• Fully accredited, full-service, 376 bed, nonprofit community medical center.
• The South Bay’s first hospital, founded in 1971
• Highest recognition in the community for quality and state-of-the-art medical services in a 2004 survey conducted by National Research Corporation.
• Selected as a Top 100 U.S. Hospital (2004, Solucient).
• Accredited by the American College of Surgeons Cancer Program
• Hospital cancer registry, with 1300 incident cases/year
• Physicians at Health Care Partners Medical Group admit to TMMC
• A 377-bed-state-of-the-art County facility built in 1987

• In 1992, Olive View incorporated UCLA in its name becoming Olive View-UCLA Medical Center

• In May 1997, Olive View-UCLA Medical Center became a part of ValleyCare, a healthcare delivery system for the north San Fernando Valley, Los Angeles County Department of Health Services
Where are we now at UCLA Medical Center?
VITA stands for....
"Vital Information and Tailored Assessment"

The VITA Program is the clinical arm of UCLA-LIVESTRONG Survivorship COE

http://www.cancer.ucla.edu/survivorshipcenter
Key Patient Care Activities

• **Survivorship Consultations and Care Plans for Adult Survivors of Cancer**
• **Long-term follow-up clinic for childhood cancer survivors**
• **Adult Survivors of Childhood Cancer: Consultations and Coordination of Care**
• **Symptom Management in Cancer Survivors**
UCLA’s Jonsson Comprehensive Cancer Center

and UCLA Medical Center

“Best in California”
Shared-Care Model

• Focus on use of the treatment summary and survivorship care plan to coordinate care with PCP
• Empower patients by giving them a copy of the treatment summary so that they can share with other providers
When does long-term survivorship begin?

• Definitional problems…should it begin at the moment of diagnosis when treatment decisions are being made?
• The eye is in the beholder…for some patients and providers, it is only many years later, or after some of the late effects are apparent
• Problem of labeling
Survivorship Health Care Delivery

• Ganz’s Three P’s of Survivor Care
  – Palliation
  – Prevention
  – Health Promotion
Symptom Management/Palliative Care: An Integral Part of Survivorship Care

• **Definition of Palliative Care:**
  – Medical care or treatment that concentrates on reducing the severity of disease symptoms (particularly if there is not a curative medical treatment)
  – Goal is to prevent and relieve suffering and to improve QOL for people facing complex illness

• **Focus on the most severe and prolonged symptoms**
Common Palliative Care Concerns

• Pain
• Fatigue
• Depression
• Physical limitations
• Cognitive changes
• Lymphedema
• Sexual dysfunction
• Menopause related symptoms
• Body Image
Consultant Specialists Required

• Mental health
• Pain management
• Physical medicine/vocational rehab
• Endocrinology
• Cardiology
• Gynecology/fertility
• Pulmonary
• Neurology/neuropsychology
Prevention

• Systematic ongoing follow-up required for screening
  – **Goal**: early detection and early intervention for potentially serious late-onset complications e.g., cataracts, osteoporosis, cardiac disease
  – Chemoprevention when available
  – Life style modification to prevent second cancers
Health Promotion

• Health promotion counseling
  – **Goal**: promote risk reduction for health problems that commonly present during adulthood (esp. for childhood cancer survivors)
  – Avoid weight gain
  – Increase physical activity
  – Avoidance of exposures that are harmful
  – Decrease risk of other chronic diseases, e.g. diabetes, heart disease
Cancer Care Trajectory

Start Here

Diagnosis and Staging

Treatment With Intent to Cure

Medical Outcomes and Quality of Life

Cancer-Free Survival

Recurrence/Second Cancer

Survivor health care delivery:
Palliation, Prevention and Health Promotion

Risk assessment and intervention at diagnosis

Safer therapies
The mission of the UCLA-LIVESTRONG™ Survivorship Center of Excellence is to facilitate improvements in the quality of life and quality of care of cancer survivors in the Los Angeles region and wherever they may reside.