


Pain in Long Term Survivors of Cancer:  
Every Nurse's Responsibility  
2010



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Long Term Survivors of Cancer:  
Every Nurse's Responsibility

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Today's Focus

1. Survivors of **ADULT** cancers
2. Common sequelae and pain syndromes associated with long term survival
3. Strategies to manage sequelae of cancer & cancer treatment
4. Resources for enhancing survivorship care

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Defining a Cancer Survivor...?

- Individuals who are more than 5 years beyond diagnosis (Mullan)
- Anyone from diagnosis through the balance of life (NCCS)
- Including family and friends (NCI)
- Individuals who have completed treatment and are in remission ?????
- What about those surviving with active disease?

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# Pain in Long Term Survivors of Cancer: Every Nurse's Responsibility 2010

## The Good News...

- In the U.S., survivors of cancer are a growing minority population
  - 67% of adults diagnosed with cancer can expect to be alive in five years
  - 75% of pediatric cancer survivors will be alive after 10 years

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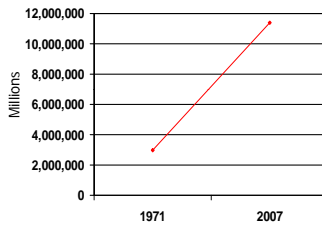
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## Nearly 12 Million Survivors of Cancer in U.S.

- Nearly 12 million living who have had cancer diagnosis<sup>1</sup>
- Widespread screening efforts have led to early diagnosis, better prognosis<sup>2</sup>
- Advances in cancer treatment have improved survival<sup>2</sup>
- Prolonged adjuvant therapies



1. National Cancer Institute, National Institutes of Health. Estimated US Cancer Prevalence. Accessed on May 7, 2010 at <http://cancercontrol.cancer.gov/ocs/prevalence/prevalence.html>.  
2. Hewitt M, et al. Committee on Cancer Survivorship. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.

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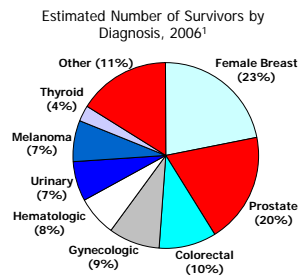
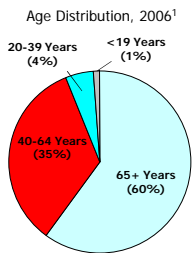
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## Characteristics of the Current Survivors



1. National Cancer Institute, National Institutes of Health. Estimated US Cancer Prevalence. Accessed May 7, 2010, from <http://dctps.ni.nih.gov/ocs/prevalence/prevalence.html>

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Today and the Future

- Cancer is a chronic disease for many
- Many live with disease for years, with or without treatment
- The needs of long term survivors of adult cancers are not clearly understood or met
- Few evidence based guidelines exist for health care of survivors of **adult** cancers

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Survivor Issues & Unmet Needs

- Secondary health problems (53%)
  - **54% chronic pain**
  - 33% infertility
- Non-medical support
  - 49% needs unmet
  - 53% practical & emotional consequences of cancer often harder than medical issues
- Emotional support
  - 70% deal with depression
  - 78% did not seek professional help

Lance Armstrong Foundation LIVESTRONG™ poll n=1020

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Survivor Issues & Unmet Needs  
(cont'd)

- Relationships
  - 58% dealt with loss of sexual desire &/or sexual function
- Financial problems
  - Decreased income (43%)
  - In debt from treatment (25%)
  - Turned down treatment option due to cost (12%)
- Job issues
  - Lack of advancement, demotion or job loss (32%)
  - Trapped in job to preserve health insurance (34%)

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Looking forward...

- This population is growing in number
- Many long term consequences can be treated or managed, some can be prevented
- Majority of long term oncology care is from primary care providers in community settings

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The Problems...

- We don't really know much about what to do...
  - Incomplete or non-existent guidelines for long term survivors of most adult cancers
  - Lack of education for health care professionals
  - Lack of information about & for survivors of adult cancers
- No national/international data base to follow long term survivors

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Published Initiatives in the U.S.

- **State of the Science Symposium on Nursing Approaches to Managing Late and Long Term Effects of Cancer and Cancer Treatment**  
*The American Journal of Nursing, 2006*
- **From Cancer Patient to Cancer Survivor: Lost in Transition**  
• Institute of Medicine, 2006
- **A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies**  
• Centers for Disease Control & Lance Armstrong Foundation, 2004
- **Imperatives for quality cancer care: access, advocacy, action and accountability**  
• National Coalition for Cancer Survivorship, 1996
- **Living Beyond Cancer**  
• President's Cancer Council, 2004
- **National Cancer Institute Office of Cancer Survivorship**
- **American Cancer Society**
- **Oncology Nursing Society**
- **American Society of Clinical Oncology**

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Selected Recommendations

- See cancer survivorship as a distinct phase of cancer trajectory & care
- Develop evidence-based clinical practice guidelines for long term follow-up care
- Create individual written summaries of care with a plan for follow-up and health promotion after completion of initial therapy (Survivor Care Plan)

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The bottom line...

- Physiologic and psychosocial consequences of cancer and its treatment can be substantial and varied
  - Some experience few long term effects, others suffer permanent and disabling symptoms that impair normal function
- Once identified, sequelae can be prevented, treated or managed
- Survivor needs are often unmet
- Health care system does not address survivorship

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Deb..  
The *real* story



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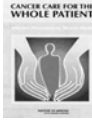
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Potential Psychosocial Sequelae:  
Long Term Survivors of Adult Cancers

- Cognitive changes
- Family issues
- Psychological distress and coping
- Body image changes
- Depression
- Anxiety
- Changes in self-esteem
- Fear of recurrence
- Changed relationships/family distress
- Economic challenges
  - Employment
  - Life and health insurance
- Coping



Curtiss CP & Haylock PJ (Eds.) State of the Science on Nursing approaches to Late & Long Term Sequelae of Cancer and Cancer Therapy. *A/N* March 2006, suppl.

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Potential Spiritual/Existential Sequelae:  
Long Term Survivors of Adult Cancers

- Renewed view of the meaning of life
- Changed view of self
- Changed view of place in the world/community/family
- Uncertainty
- Changes in religious values and beliefs
- Persistent suffering
- Dealing potentially life-threatening illness

Curtiss CP & Haylock PJ (Eds.) State of the Science on Nursing approaches to Late & Long Term Sequelae of Cancer and Cancer Therapy. *A/N* March 2006, suppl.

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**It's not over  
when treatment ends!**

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Note!

- Sequelae occur anytime from pre-diagnosis to many years after therapy
- Many either haven't been told or did not remember being told
- Many did not make the connection between current health status and past cancer or cancer therapy

Curtiss, Haylock and Hawkins (2006) *AJN* 106(3):48-52

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One Minute Screening

- "What was your treatment for cancer?"
- "Do you have or think you have any health problems related to your cancer or cancer treatment?"
- If "yes" or "I think so", ask,
  - How are you managing the problem?
  - Would you like help dealing with it?

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- Acknowledge person's concerns
- Coordinate evaluation and management
- Refer if needed
- Identify local, written and electronic resources for long term survivors of cancer

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Post mastectomy syndrome

- 20% women with mastectomy or lumpectomy
  - Burning, shooting, electric shock sensations in the skin around incision
  - More common among younger women & those who are overweight
- Treatment
  - Pharmacological, including adjuvants and topical capsaicin

Polomano & Farrar, AJN, 2006

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Post thoracotomy syndrome

- 50-80% several months after thoracotomy
  - 30% may still have pain 4-5 years later
- Occurs along surgical scar, myofascial pain or frozen shoulder
- Prevention
  - Minimally invasive thoracotomy
  - Aggressive post-op pain management
  - Thoracic epidural analgesia with bupivacaine during surgery

Polomano & Farrar, AJN, 2006

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Post-Amputation Pain

- Localized at site of amputation
- Referred ("phantom")
  - Neuropathic central pain
- 66% report phantom pain at 6 months
- Pharmacologic treatment
  - Antiepileptics, TCAs, NMDA receptor antagonists

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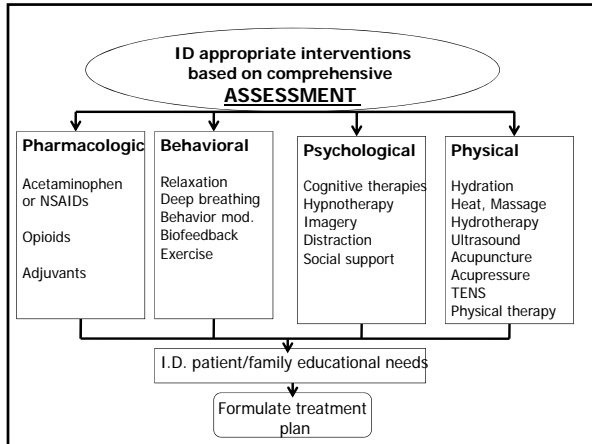
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## Pharmacologic Management of Neuropathic Pain

- Current practice: "trial and error"
- May only obtain a limited response:
  - 50% relief in about 50% of persons
- There may be advantages to combining two drugs

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## Evidence-based Recommendations for the Treatment of Neuropathic Pain

- First-line:
  - Tricyclic & SNRI antidepressants
  - Antiepileptics (calcium channel modulators),
  - Topical lidocaine
- Second-line:
  - Opioids and tramadol; these might be first-line in certain circumstances
- Third-line:
  - Mexiletine, NMDA-receptor antagonists, topical capsaicin

Dworkin, R. H., et al. 2007. (Pharmacologic management of neuropathic pain: evidence-based recommendations. *Pain*, 132(3), 237-251.

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# Pain in Long Term Survivors of Cancer: Every Nurse's Responsibility 2010

## The Evidence

- Hx and PE
- Psychosocial evaluation
- Appropriate diagnostics
- Individualized plan
- Multimodal interventions
  - Physical or restorative therapies
  - Cognitive behavioral therapies, biofeedback, relaxation training, group therapy and counseling
- Multi-modal interventions (cont'd)
- Anticonvulsants, TCAs, SNRIs, opioids, NMDA receptor antagonists & topical agents as part of multimodal strategy for a variety of chronic pain conditions

American Society of Anesthesiology Practice Guidelines, Anesthesiology, April 2010

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## EBP: Interventional therapies for neuropathic pain

- Cryoablation for selected patients
  - E.g.: peripheral nerve pain
  - Post-thoracotomy pain syndrome
- Subcutaneous peripheral nerve stimulation if no response to other therapy
- Conventional radiofrequency ablation for neck pain
- Celiac plexus blocks for chronic pancreatitis

American Society of Anesthesiology Practice Guidelines, Anesthesiology, April 2010

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## Interventional (cont'd)

- TENS for neck and phantom limb pain
- Epidural steroid injections for radicular pain or radiculopathy
- Intrathecal preservative-free steroids for intractable post-herpetic neuralgia
- Peripheral somatic nerve blocks should not be used for long-term treatment of chronic pain

American Society of Anesthesiology Practice Guidelines, Anesthesiology, April 2010

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## Lymphedema

- Lifelong, chronic accumulation of lymph in interstitial space causing swelling
- Prevalence
  - 30% women with breast cancer; also with some prostate, ovarian, & abdominal cancer sites & elsewhere
- Issues
  - Pain, constant discomfort, body image issues, anxiety, depression, stigma, feeling handicapped
  - Time off from work (80% with lymphedema)
  - Affects employment status (9%)

Fu & Rosedale, J Pain Symp Manag 2009; 38:849-859.

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## Lymphedema Management (cont'd)

- Long term goals
  - Decrease swelling
  - Relieve symptom distress
  - Prevent acute exacerbations & infection
  - Provide psychosocial support

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## Lymphedema Management

- Early diagnosis is vital
- Risk reduction/management
  - Ideal body weight, healthy lifestyle
  - Normal exercise with gradual increase
  - Prevent infection
    - Maintain skin integrity
    - Avoid trauma/injury
  - Compression sleeve at first notice of swelling
  - Prophylactic anti-fungal powder & diabetic foot care for lower extremity lymphedema

National Lymphedema Network [www.lymphnet.org](http://www.lymphnet.org)

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Managing Lymphedema (cont'd)

- Assess for signs of infection, degree of swelling, coping etc.
- Treatment options
  - Comprehensive decongestive physiotherapy
    - Manual drainage
    - Bandaging
    - + skin care/diet
    - Compression garments
    - Self-manual drainage
  - Infection
    - Antibiotic therapy
    - Rest, elevation of affected limb, ↑ fluids
  - Pain
    - Comprehensive assessment
    - Initiate plan appropriate to the type and intensity of pain

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Lost in Transition:  
Survivors of Adult Cancers

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Essential Components  
of Survivorship Care

- 1) **Prevention** of recurrent and new cancers, and other late effects;
- 2) **Surveillance** for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
- 3) **Intervention** for consequences of cancer and its treatment;
- 4) **Coordination** between specialists and primary care providers to ensure that all of the survivor's health needs are met.

From Cancer Patient to Cancer Survivor: Lost in Transition (IOM, 2006)

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## Why a Survivorship Care Plan?

1. Summarize & communicate what transpired during cancer treatment
2. Describe known & potential late effects with expected time course
3. Communicate to survivor and HCPs what has been done and what needs to be done
4. Promote a healthy lifestyle to reduce risk of recurrence & manage co-morbidities

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## The Cancer Survivor's Prescription for Living

*Nurses must take the lead in planning care for survivors.*



Haylock PJ, Mitchell SA, Cox T, Temple SV, Curtiss, CP. (2007). *American Journal of Nursing*, 107(4)58-70.

The long fight by Dr. Anne Howard of South Africa, who led all by a health care provider in the 1980s, is chronicled in the article, "Prescription for Living: The Cancer Survivor's Prescription for Living." For more information about the article, visit <http://dx.doi.org/10.1097/01.NRN.0b013e3180151111>.

58 APRIL 2007 VOL 107 / NO 4

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## "Prescription for Living"

AJN, April 2007

- Treatment summary
- Potential late and long term effects and what to do about them
- Screening and follow-up recommendations
- Prescription for wellness
  - Nutrition, optimum weight
  - Exercise
  - Health maintenance strategies
  - Smoking cessation
  - Other issues

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Survivorship Care Plan Templates

- American Society of Clinical Oncology  
[www.cancer.net/patient/Survivorship](http://www.cancer.net/patient/Survivorship)
- Lance Armstrong Foundation
- [www.livestrong.org](http://www.livestrong.org)
- University of Pennsylvania  
[www.oncolink.org/oncolife](http://www.oncolink.org/oncolife)
- Other site-specific advocacy group web sites

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YOU Can Help!

- See survivorship as a phase of cancer and cancer treatment
- Learn more about late effects and long term sequelae
  - Be on the lookout for them in your patients
- Ask for end of therapy treatment summaries and a written plan of care for follow-up
- Screen for late effects in anyone with a history of cancer to identify problems early
- Support wellness strategies
- Connect survivors with resources
- Establish systems to care for long term survivor needs
  - Education for HCPs
  - Survivor clinics

Curtiss, Haylock and Hawkins (2006) *A/N* 106(3):48-52

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Cultural Differences

- Few studies have addressed the needs of survivors who are minorities or are medically underserved
- Adapt assessment to recognize and address the socioeconomic and cultural variables that affect adaptation to and survival from cancer among diverse groups

Curtiss, Haylock and Hawkins (2006) *A/N* 106(3):48-52

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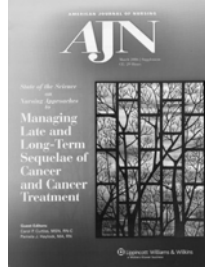
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Resources...

Nursing Approaches to  
Managing Late and  
Long Term Sequelae  
of Cancer & Cancer  
Therapy

Collaborators  
American Journal of Nursing, National Coalition for  
Cancer Survivorship, American Cancer Society and  
others with a grant from AHRQ and other  
supporters



AJN Supplement, March 2006;  
[www.ajnonline.com](http://www.ajnonline.com)

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Cancer Survivors' Tool Box  
[www.canceradvocacy.org](http://www.canceradvocacy.org)



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Health Insurance & Survivors



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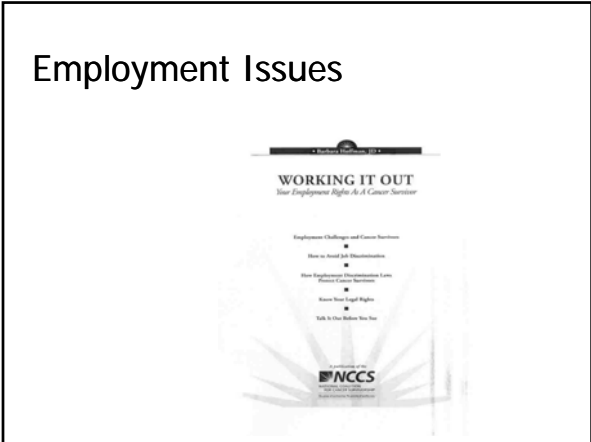
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