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"Hello, Mr. Busino. I understand you're suffering  
from some drug side effects."

# *The Journey Forward*

*Guiding Survivors as they  
move ahead*



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November 6, 2009*



*“From the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a **survivor.**” (NCCS)*

# The Good News

- ◆ Cancer survivorship numbers are growing!
- ◆ 12 million survivors living in the United States today but...
- ◆ Cancer treatments are not without consequence.
- ◆ Survivors often deal with long term effects with little guidance.
- ◆ No mention of the quality of that life nor of the status of disease:
  - Remission: short-term, long-term
  - Active disease: active observation, ongoing therapy

# Survivorship issues

- ◆ Physical Well-Being
- ◆ Emotional/psychological Well-Being
- ◆ Social/Sexual Well-Being
- ◆ Financial Well-Being

# Side effects post therapy

- ◆ Predominant complaints are:
  - Fatigue
  - Shortness of breath
  - Cognitive changes
  - Neuropathies

# Fatigue



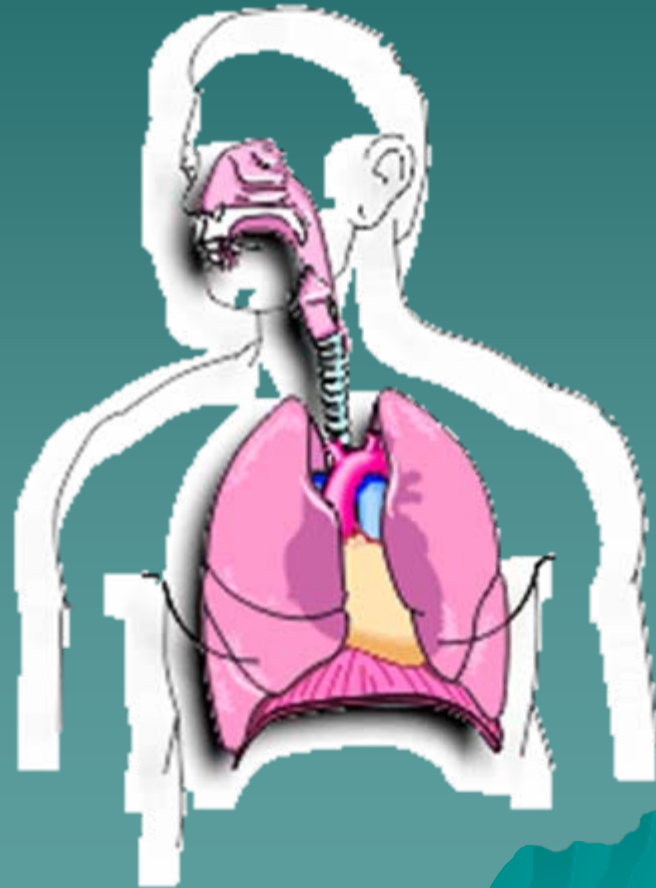
- ◆ Most common side effect
- ◆ An overwhelming physical, emotional, and mental exhaustion
- ◆ Weeks to months post therapy
- ◆ Need to rule out associated problems
  - Anemia
  - Pulmonary changes
  - Cardiovascular changes
  - Depression/Anxiety
  - Sleep Hygiene
  - Nutrition:
    - ◆ anorexia,
    - ◆ prolonged GI distress

# Managing Fatigue

- ◆ Treat underlying cause
- ◆ Light exercise (walking 3-5x/ wk)
- ◆ Learn to control your fatigue
  - Prioritize tasks
  - Delegate
  - Rest periods

# Shortness of Breath

- ◆ Secondary to chemotherapy and/or radiation therapy
  - Anemia
  - Pulmonary fibrosis
  - Cardiomyopathy
  - Deconditioning
- ◆ Can be improved with pulmonary rehabilitation



# “Chemo Brain”

- ◆ 17-75% of patients report some cognitive impairment.
  - Short term memory
  - Multi-tasking
  - New learning
  - Reading comprehension
  - Decrease in concentration
- ◆ Cumulative- more chemotherapy could cause greater deficits
- ◆ Usually improves over time.
- ◆ Stimulants may be of help: Ritalin, Adderall, Concerta, Provigil
- ◆ Herbal tx: ginkgo biloba, ginseng
- ◆ Cognitive rehabilitation- puzzles, sudoku
- ◆ Adequate sleep, healthy diet, underlying diagnoses (thyroid)

# Neuropathies

- ◆ Peripheral Neuropathy-damage to nerves causing numbness, 'pins and needles", tingling, burning, fine motor skills
- ◆ Offending agents:
  - Vinca alkaloids
  - Bortezomib
  - Thalidomide
- ◆ Cumulative, potentially reversible
- ◆ Treatment and/or management
  - Vitamin B6 daily
  - Gabapentin
  - TCA

# Potential Complications

- ◆ Heart (CAD, HTN)
- ◆ Lung (fibrosis)
- ◆ Osteoporosis
  - Decrease in bone density (LT steroids etc.)
  - Exercise, calcium/ vit D supplements, Dexa
- ◆ Endocrine
  - ◆ Thyroid (under or over active thyroid)
  - ◆ Reproductive
- ◆ Monitoring

# Secondary Cancers

- ◆ Related to use of chemotherapy agents and/or radiation
- ◆ Risks increase with multimodality therapy and more aggressive regimen, e.g. autoPBSCT
- ◆ Reported neoplasms
  - Leukemia (AML)
  - NHL
  - Lung
  - Breast
  - Melanoma
  - Colon
- ◆ Monitoring/Screening

# Techniques To Maximize Health

- ◆ Healthy diet and weight maintenance
  - Vitamins
  - Supplements?
- ◆ Cancer Rehabilitation/Exercise programs
- ◆ Preventative medicine
  - Screening
  - Immunizations

# Health Maintenance

- ◆ Keep regular follow-ups
- ◆ Screening exams (mammograms, pap, colonoscopy, skin exam, thyroid, HTN)
- ◆ May need earlier screening depending on therapy
- ◆ Healthy diet, weight management, stop smoking, sunscreen, limit alcohol
- ◆ Immunizations- no live vaccines!
  - Seasonal influenza vaccine
  - Pneumococcal vaccine every 5 years
  - H1N1- to consider

# Sexual and Reproductive Issues

## ◆ Libido

### – During chemotherapy

- ◆ Effects of chemotherapy/hormonal therapy/radiation
- ◆ Emotional aspects

### – After therapy

- ◆ What is normal?

### – Medical aids

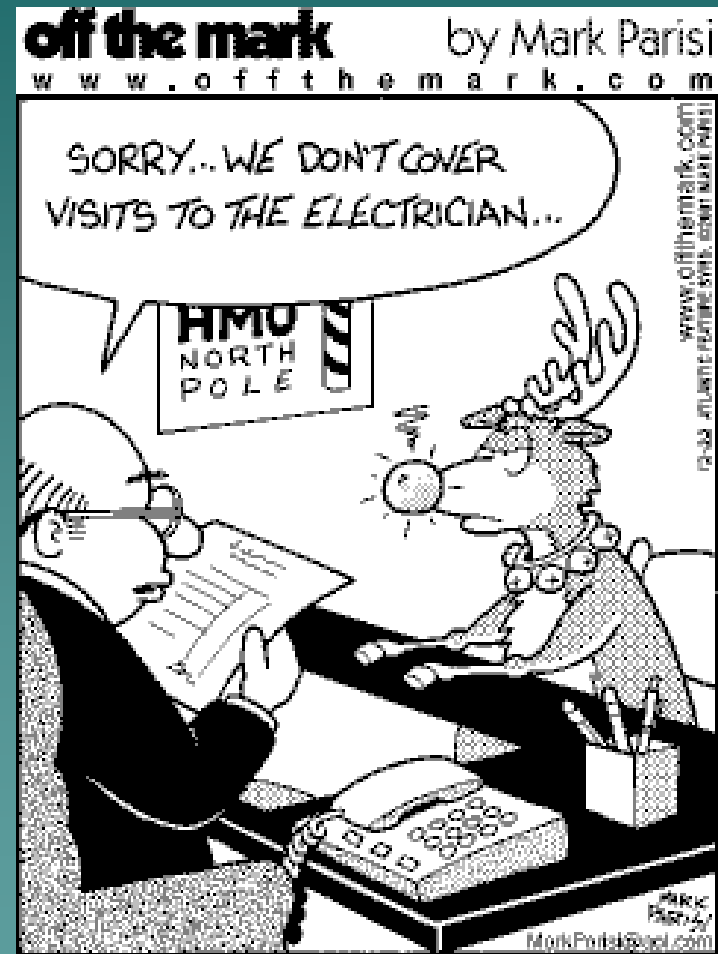
- ◆ Viagra/Cialis
- ◆ Testosterone patches
- ◆ Estrogen: oral, topical
- ◆ Antidepressants

# Sexual Issues in Women

- ◆ Fertility concerns
  - Birth control during/ after
  - Fertility specialist ([fertilehope.org](http://fertilehope.org))
- ◆ Symptoms caused by sudden onset of menopause from chemotherapy
  - Dryness, pain, decreased libido, hot flashes, irritability
  - Lubricants, estrogen replacement

# Financial Aspects

- ◆ Medical Insurance
  - Legal protections
- ◆ Work/Family Leave
  - Career trajectory
- ◆ Disability
  - Short term
  - Long term
- ◆ Advance directives/ Living Wills



# LIVESTRONG CARE PLAN

POWERED BY  
Penn Medicine's **OncoLink**

- ◆ The LIVESTRONG Survivorship Center of Excellence Network
  - Provide essential direct survivorship services
  - Empower yourself and take control about your cancer care needs
- ◆ <http://www.livestrongcareplan.org/>  
PENN 215-615-3371

# LIVESTRONG CARE PLAN

POWERED BY  
Penn Medicine's **OncoLink**

- ◆ Electronic tool for survivorship care plan
- ◆ You will be asked a short questionnaire
  - Demographics
  - Type of cancer
  - Type of therapy: XRT/Surgery/Chemotherapy
- ◆ Can be used by primary care physicians, oncologists, or patients

# LIVESTRONG CARE PLAN

POWERED BY  
Penn Medicine's **OncoLink**

- ◆ Typical care plan
  - Patient diagnosis and treatment summary
  - Best schedule for follow-up tests
  - Information on late effects of cancer
  - List of symptoms to look for
  - Specific cancer therapy related complications

# Additional Resources

- ◆ Leukemia Lymphoma Society
- ◆ <http://www.cancer.net/patient/Survivorship> (ASCO)
- ◆ <http://www.canceradvocacy.org/>
- ◆ [www.CancerCare.org](http://www.CancerCare.org)
- ◆ American Cancer Society-Cancer.org
- ◆ Employee assistance programs
- ◆ Fertile Hope

# “Sharing the Wealth”



- ◆ Share your experience
  - Peer connection programs
  - Advocate for yourself and others
- ◆ Volunteer your time
  - Light the Night
- ◆ Participate in surveys/Clinical Trials on survivorship