Breast Cancer Survivorship: A Roadmap

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What is Cancer Survivorship?

- A person with cancer is considered a “survivor” from the time of diagnosis.

- Many groups include caregivers, family and friends in the definition as well.

- However, in clinical practice, survivorship care typically begins at the end of active treatment.
  - After chemo, radiation, surgery. Adjuvant hormone therapy is taken during survivorship phase.

- Over 13 million cancer survivors in the US alone!
I’m a Survivor, Now What?

- Leaving the “comfort” of frequent visits with the oncology team can be a very difficult transition.
- When will I be back to normal?
- Survivors may not be aware of the potential concerns or late effects of treatment.
- You must be your own advocate!
Institute of Medicine Report

- Published in 2006 by an expert panel.
- PCPs and other non-oncology HCPs are not aware of long term effects related to cancer therapy.
- Seldom receive guidance from oncology community.
- Most survivors will transition to PCP led care, seeing oncology infrequently, if at all.
- Survivors not informed about how to manage the transition.
Institute of Medicine Report

- Recommended:
  - More research initiatives
  - Increase awareness
  - Increase communication between providers
  - All survivors should receive a treatment summary and a survivorship care plan to address medical, psychological, financial and lifestyle issues
What is a Treatment Summary?

- A document that summarizes the cancer diagnosis & treatments
  - Relevant pathology results
  - Surgery
  - Medical therapies (chemo, hormone, biotherapy)
  - Radiation therapy
- No “right way” to do this!
What is a Survivorship Plan?

- A survivorship plan is a document that outlines possible health risks, psychosocial effects, financial effects and genetic risk related to cancer and cancer therapy.
- How to reduce health risks, when possible, through healthy lifestyle and preventive therapies.
- How to monitor for late effects with your healthcare team.
- Follow up care & other screening.
- Referrals for follow up care and resources.

OncoLink

Abramson Cancer Center of the University of Pennsylvania
How Do I Get a Survivorship Plan?

- Talk with your oncology team (clinicians have access to several care plan builders from ASCO & Journey Forward)
- Visit a Late Effects / Survivorship Clinic
  - Find one: www.oncolink.org/survivor/clinics
- Create a LIVESTRONG Care Plan at livestrongcareplan.org
- *What’s Next? Life After Cancer Treatment* booklet from Minnesota Cancer Alliance at www.mncanceralliance.org/scp.html
Resources for Survivorship Information

- National Coalition for Cancer Survivorship: www.canceradvocacy.org
- Office of Cancer Survivorship: dccps.nci.nih.gov/ocs
- ACS / GWU National Cancer Survivorship Resource Center: www.cancer.org/survivorshipcenter
- OncoLink, ACS, CancerCare, LIVESTRONG, cancer.net
Learning about late effects can be overwhelming, but remember:

- Some survivors will have no long term effects, some will have many, but most will be somewhere in between.

- Educating yourself allows you to be your best advocate.
Follow Up Care

- Mammogram annually
  - After lumpectomy, have first mammogram at 6 mos. after radiation, then annually
  - Breast self-exams
  - After double mastectomy, examine chest wall for swelling and rash, notify oncologist of any changes
- See oncologist every 4-6 mos. for 5 years, then annually
- No routine scans
- Consider genetic counseling / screening
Hormone Therapy

• Importance of taking as directed!
  • Managing side effects: hot flashes, vaginal dryness, AI joint pain, weight gain

• Tamoxifen:
  • Report any vaginal bleeding, Gynecology eval yearly
  • Seek care if any symptoms of a blood clot: unilateral leg swelling, redness, pain

• AIs:
  • Baseline Dexa Scan to evaluate bone health
Healthy Living After Cancer

- Quit smoking / tobacco use or don’t start

- Healthy weight, balanced diet & regular exercise
  - 30 mins of moderate to vigorous activity per day, 5 days a week.
  - Plenty of fruits and vegetables daily. Strive to have 2/3 of your plate be vegetables, fruits, whole grains and beans, while 1/3 or less should be an animal product. Limit red and processed meats.
  - Learn more in the AICR’s Guidelines for Survivors and the ACS Eat Healthy and Get Active information on their websites.
Healthy Living After Cancer

- Cancer screenings & prevention for other cancers
  - i.e. sun protection, colonoscopy, pap testing
- Limit alcohol intake – if at all – to 1 drink/day for women and 2 for men
- Regular check ups & health screenings (cholesterol, blood pressure, blood sugar)
- Flu shot, pneumococcal vaccine
- Dental & eye health
Common Survivor Issues

- Fatigue
- Bone Health / Osteoporosis
- Sexuality & Intimacy concerns
- Weight gain
- Neuropathy
- “Chemo Brain”
- Fertility
- Anxiety, fear of recurrence
- Practical concerns
Fatigue

- Survivors should consider & treat other causes: thyroid disorders, pain, anemia, nutrition, depression, poor sleep

- Exercise!
  - Improves mental and physical functioning, overall fitness & sense of well being.
  - How much and type of activity depends on your overall health and what you can tolerate.
Fatigue

- How’s your sleep?
- Complementary therapies: acupuncture, Reiki, Yoga
- Nutrition tips: keep hydrated, 5-6 small meals per day can help boost your energy without the fatigue that sometimes comes with large meals. Be sure to include some protein sources such as hard boiled eggs, nuts or peanut butter or low fat dairy foods, such as cheese, yogurt or cottage cheese.
Bone Health

- Osteoporosis & osteopenia are decreases in bone density ("bone thinning"), which increases risk of fracture.

- Increased risks from cancer: chemotherapy, long term steroid use, early menopause, aromatase inhibitor use, radiation to spine, hips or legs.

- Other risk factors: women, Caucasian, Asian, Latino descent, menopause, low body weight (small/thin), family history, inactivity, poor diet, smoking, alcohol use
Bone Health

- Prevention:
  - Avoid smoking, alcohol & caffeine
  - Weight bearing exercise 2-3 times per week
  - Calcium intake 1000mg (<50yo), 1200mg (>50yo) per day. Take broken into smaller amounts, take supplements with food.
  - Vitamin D 400-800iu (<50), 800-1000iu (>50) per day
  - Consider Dexa Screening
  - National Osteoporosis Foundation: www.nof.org
Common Sexuality/Intimacy Concerns Post Treatment

- For Women:
  - Vaginal dryness / painful intercourse
  - Positional pain

- For Men:
  - Erectile dysfunction

- For Both:
  - Decreased Libido
  - Body image
  - Anxiety/fear
Tips for Managing Sexual Concerns

- May be medication induced- check other medications.

- For women experiencing vaginal dryness or pain using vaginal moisturizers applied 2-3 times per week (Replens, SilkE) plus lubricants used during sexual activity (Astroglide, K-Y jelly) may help.

- For men experiencing erectile dysfunction there are numerous remedies such as oral medications, penile injections, vacuum devices, and implant or prosthesis.

- Positioning changes to manage pain

- Can be physical and psychological- taking baby steps such as touching, massage, etc. with partner may help loss of desire or low libido.
Tips for Managing Sexual Concerns

- Remember there is intimacy without intercourse- It’s a matter of rediscovering what feels good.
- Set the mood – what sparked romance before cancer? Music, a romantic meal? Take your time and enjoy each other!
- Communication is crucial!
- While these are physical concerns, sexuality includes more than that – how you view yourself, how your partner views you, etc. Care for the whole picture.
- Some will benefit from working with a therapist- look for one with experience in working with people with cancer and/or sexual and relationship issues.
- Dating – [LBBC article](#)
Weight Gain

- Not uncommon after breast cancer – can be related to menopause, less time/energy for exercise, diet changes

- Healthy diet – helps with weight gain, but also helps decrease recurrence and prevention for other cancer types

- Exercise - helps with weight gain, fatigue and reduces recurrence in some cancers

- [www.aicr.org](http://www.aicr.org), Apps for weight loss, exercise tracking
Peripheral Neuropathy

- Ranges from pins & needles, numbness to painful burning. Can be in fingers/hands, toes/feet.

- Can improve over time, but not always.

- Safety concerns – i.e. temperature, tripping hazards, fine motor skills

- Physical & occupational therapy, rehab medicine (physiatrist)

- Medications for pain (neurontin, Lyrica, Cymbalta)
“Chemo Brain”

- Cognitive changes during and after treatment; memory and concentration troubles, short term memory, reading comprehension, multi tasking
- Tools to help memory (calendars, to do lists), games to exercise your brain, have a routine
- Get enough rest and sleep, healthy diet.
- Exercise your body- it makes you feel more alert.
“Chemo Brain”

- Cognitive rehabilitation with an occupational therapist can be helpful.
- Yoga can help with focusing; Mindfulness increases working memory and resistance to distraction.
- Medications being studied, but none proven useful.
- Know your limitations, ask for help.
- Keep a positive outlook and try to find some humor in your chemo-brain moments!
Fertility

• Survivors wondering about their fertility should see an oncofertility specialist who can evaluate them.

• Risk of infertility varies greatly depending on age, 3 Ds of chemo- drug, dose, duration, other treatments (surgery, radiation to reproductive organs OR the brain).

• Women can be at risk for early menopause.

• Ideally addressed before treatment, but this is not always possible.
Psychosocial Impact

- Anxiety, Depression and Traumatic Stress
- Fear of Recurrence
- Renewed Optimism: Embracing Survivorship
- Practical Matters
Anxiety and Depression in Cancer Survivors

- Worry and sadness are to be expected and are NORMAL emotions when coping with a cancer diagnosis, treatment and transitions in care
- (Only) about ¼ of cancer patients will be diagnosed with a major depressive disorder
- Some level of distress is NORMAL
When To Be Concerned

- **DEPRESSION**
  - Symptoms lasting greater than 2 weeks including:
    - sadness, isolation, agitation, fatigue, feelings of worthlessness, decreased ability to concentrate, lack of interest in activities, changes in sleep and eating habits
  - Strategies used previously to aid in coping do not work
  - Symptoms result in distress and social, occupational and functional impairment
  - Notify your clinician immediately, especially if you have suicidal thoughts

- **ANXIETY**
  - Symptoms of excessive anxiety and worry occurring most days of the week for at least 6 months
  - Strategies used previously to aid in coping do not work
  - Symptoms include restlessness, fatigue, difficulty concentrating, irritability, muscle tension and sleep disturbance
  - Symptoms result in distress and social, occupational and functional impairment
Psychosocial Impact of Survivorship

• Survivorship can also emphasize other stressful situations related to your cancer diagnosis and treatment including:
  • Asking for and receiving help
  • Differences in your physical abilities
  • Alteration to appearance and body image
  • Threats to self-esteem and well being
  • Fear of your cancer coming back
  • The necessity to disrupt or change plans for the future
  • Financial problems related to cancer treatment
  • Relationship issues
  • Fear of burdening others
Post Traumatic Stress

- Cancer diagnosis, treatment and side effects can be traumatic
  - Recent study found 1/3 cancer patients experience PTSD symptoms (http://www.huffingtonpost.com/2011/10/15/cancer-ptsd-symptoms-survivors_n_1008990.html)
- Can involve intrusive thoughts, nightmares, suggestive anxiety, avoidance of reminders of the event, decreased interest in activities, detachment, flat/unemotional affect, inability to see/plan for the future
Fear of Recurrence

- Facing the reality of recurrence
  - What if this happens?
  - Waiting for the shoe to drop?
  - Could I go through treatment again?
  - What options are left for me?
  - Scan-xiety
  - What if it DOESN’T happen?
    - Balancing reality, hope, optimism and a natural inclination to “prepare for the worst”
Questions to ask your treatment team about recurrence

- Is it possible the cancer can come back?
- When is it most likely to come back?
- Where would it most likely come back?
- How likely is it to come back? (numbers and statistics)
- Is there anything I can do keep it from coming back?
- How will I know if it's back? What should I look for?

Living with Uncertainty

- Be aware of certain events that may heighten your feelings (anniversary of diagnosis, anniversary of end of treatment, upcoming scans, upcoming appointments)

- Realize and accept your lack of control in the situation

- Communicate your emotions and fears with your support persons and your treatment team

- Utilize methods of relaxation and complimentary medicine to help cope with stress and anxiety

- Maintain physical activity; maintain mental activity!

- Give yourself permission to be optimistic and hopeful, despite the reality and possibility of recurrence
What can I do?

- Utilize your Survivorship Care Plan
- Communicate with your care providers—ALL OF THEM
- Maintain your health insurance
- Keep ALL appointments; get all scans, lab draws
  -- Even if you feel TOTALLY FINE!
Renewed Optimism: Coping With & Embracing Survivorship

- Recognize the nature of **ADAPTABILITY**
  - “The art of winning in a time of uncertainty” (Max McKeown)

- Be aware of your own capacity for **RESILIENCE**
  - “The ability to find inner strength and bounce back from a challenge”

- Allow and embrace your **STRENGTHS**

- Acknowledge and grieve **LOSSES**
  - Connections with treatment team, other patients

- Recognize there are things to be **GAINED**
  - Hair, appetite, strength, vigor, interest in activities, meaning
Practical Concerns

- Returning to work
  - How is my disability impacted?
  - What if I can’t do the job I did before?
    - Reasonable accommodations and the ADA
  - I’m scared about disclosing my cancer history to a potential new employer
  - Do I have to tell my co-workers?
  - What about time off for follow up appointments?
    - FMLA
Practical Concerns

- I’m afraid I’m being discriminated against because I had cancer
- I’m worried about job stress impacting my well-being!
- How will the Affordable Care Act impact my ability to maintain my health insurance?
- Will I be able to purchase life insurance now that I have a history of cancer?
Resources

- Social Security Administration
  - Working While Disabled: How we can Help
- Cancer and Careers
- Cancer Legal Rights Center
- Cancer Care
- American Cancer Society
- OncoLink
- National Coalition for Cancer Survivorship
Resources

- Peer Support Programs - Giving back!!!
  - Cancer Hope Network
  - Imermans Angels
  - Breast Cancer Connections Buddy Program
  - Cancer Support Community