



Survivorship: Life Beyond Cancer Treatment



UNIVERSITY of MARYLAND
ST. JOSEPH MEDICAL CENTER
THE CANCER INSTITUTE

AN AFFILIATE OF THE UNIVERSITY OF MARYLAND
MARLENE AND STEWART GREENEBAUM
COMPREHENSIVE CANCER CENTER



Dear Cancer Survivor,

The Cancer Survivorship program at University of Maryland St. Joseph Medical Center's Cancer Institute is designed to help patients transition from active cancer treatment to healthy active survivorship. Our goal is to address the common issues many cancer patients face after treatment.

At UM SJMC's Cancer Institute, survivors are patients who are actively receiving treatment and those who have completed initial cancer treatments. Here we support the Institute of Medicine's survivorship care recommendations, which include:

- Prevention of new cancers, and of other late effects
- Surveillance for recurrence or second cancers
- Assessment of medical and psychosocial late effects
- Interventions to help with effects of cancer and its treatment
- Coordination between specialists, oncologists and primary care providers to ensure that all of the survivor's health needs are met

As you complete treatment, our goal is to assist you with your transition back to wellness through a survivorship care program, which includes:

- Follow-up visits with your health care team
- Nutritional education and exercise recommendations
- Addressing fears of recurrence and
- Advice on how to manage long-term or late effects that may have resulted from your cancer or its treatment.

This booklet is a guide to assist you with a variety of aspects relating to your survivorship journey. It contains helpful hints on changes you may experience, links to additional resources and information on how to create a Survivorship Journal to chronicle your healthcare experience.

We hope you find the resources and support provided helpful in your transition back to greater health. If you have additional suggestions or recommendations, please feel free to share them with us.

Thank you,

Your Health Care Team

Who is a Survivor?



If you are reading this, you are!

What is Survivorship?

Definition of survivorship

the state of being a survivor: survival

What Does Survive Mean?

1. to remain alive: to continue to live
2. to continue to exist

Source: Merriam-Webster's Learner's Dictionary

What is the schedule for my follow-up care?

Oncology Visits

- You will likely see your medical, surgical or radiation oncologist, or your nurse practitioner every 1-3 months for the first year after treatment is complete.
- Visits will then decrease to every 6-12 months for the next several years.
- After five years, some patients elect to maintain their care with their oncology team on an annual basis.



Diagnostic Testing

- Not all cancer requires on-going testing
- Breast cancer patients should obtain mammogram and/or MRI at the instruction of their medical oncologist or breast surgeon.
- In general, CT scans or PET scans are not necessary for on-going follow-up care. However, for some cancers, we will order radiology tests to assess your cancer status.

Lab work

- Your medical oncologist may want to check lab work on a regular basis, depending on the treatment that you received.
- If you have labs drawn with your primary care provider or another specialist, please ask that they forward the results to your medical oncologist.



Port

- If you have a port, you will need to schedule appointments to have it flushed every 6 weeks; this is done in the Cancer Institute.
- You may elect to have your port removed after your treatment is complete; the timing for removal should be discussed with your medical oncologist.

What will happen at my follow-up appointments?

Exam

- Your medical, surgical or radiation oncologist, or nurse practitioner will perform a physical exam related to your cancer treatment.

Discussion

- Recent test results (radiology, labs, DEXA scans, etc.) will be reviewed and your questions should be answered
- Review any new problems or concerns that you are having
- Evaluation of any ongoing effects from your treatment

Plan

- Schedule your next appointment and any labs or tests that are ordered
- Arrange for referrals to specialists, dietician, etc, based on physician or nurse practitioner assessment and your needs.

When should you call between appointments?

Reasons to Call

- If you have any new symptoms or concerns that seem to be related to your cancer or cancer treatment
- If you have persistent pain that you believe may be related to your cancer
- Emotional problems, such as depression or anxiety

Types of long-term side effects and how to manage them

Fatigue

- Daily exercise helps
 - Improves fitness; helps control weight gain
 - Enhances self-esteem; strengthens immune system
 - Reduces stress; relieves depression / anxiety
 - Maintains healthy bones and joints
 - May positively influence risk of recurrence and quality of life
 - Focus on stress reduction



- Prioritize your activities; eliminate those that you can
- Maintain a regular sleep pattern / schedule
- Be sure your nutritional and hydration intake is balanced and adequate
- Types of exercise
 - Walking
 - Dancing, bike riding, aerobics
 - Yoga, Tai Chi
 - Swimming (easier on the joints) - If you are a radiation patient, please check with your nurse.
 - Fun activities with others
- In the beginning you may still need to rest as needed.

Memory Changes

- Changes you may notice
 - Difficulty concentrating; feeling mental fogginess
 - Trouble learning new things; short attention span
 - Trouble handling money
 - Forgetfulness about events during the day
 - Taking longer than usual to complete routine tasks
 - Difficulty multi-tasking
 - Short-term memory concerns
- Helpful hints
 - Discuss your concerns with your medical team
 - Write things down; keep it with you
 - Use a calendar; maintain a daily routine
 - Exercise your brain: crosswords, reading, math puzzles
 - Bring a friend to your doctor appointments
 - Be sure to get an adequate amount of sleep
 - Manage your stress level
 - Keep things in a consistent location (keys, phone, etc.) Ask for help!



Physical Changes

- Weight gain
 - Incorporate strength-building exercise into your day
 - Maintain a healthy diet; meet with a dietician
 - Be patient with yourself!
 - Focus on the positive
 - Plan meals and shopping trips
- Weight loss
 - High-calorie drinks
 - Try small, frequent meals



- Focus on your favorite foods and snacks
 - Exercise before a meal, especially walking
 - Try creative cooking; use different foods and flavors
 - Take medication if your physician orders it
 - Meet with a dietician
- **Hair loss; hair regrowth different than pre-treatment**
 - Hair usually returns 3-5 months after your last chemo treatment
 - Wear comfortable wigs, scarves, hats, or nothing if you prefer
 - Use sunscreen; your scalp has not previously met the sun!
 - Wear jewelry, make-up as you may have prior to chemotherapy
 - Avoid hair color while it grows out
 - Wear a hat when in the sun
- **Changes in body image due to surgery, radiation, or chemotherapy**
 - Be patient; adjusting to physical changes takes time
 - Talk to your medical care team about difficulties
 - Maintain daily skin care
 - Acknowledge - and grieve - losses and change
 - Manage lymphedema appropriately
- **Fatigue; pain**
 - Talk with your medical care team about your pain
 - Take medications as prescribed
 - Consider acupuncture, hypnosis, meditation, or yoga
 - Try relaxation skills and distraction
 - See a Pain Management specialist
- **Lymphedema**
 - Be sure to talk with your care team about this!
 - Physical Therapy consultation and treatment
 - See resource reference on Lymphedema
- **Menopause symptoms**
 - Irregular periods
 - Bladder or vaginal problems
 - Lack of interest in sex
 - Fatigue and sleep problems
 - Memory changes, mood swings, depression, irritability
 - Weight gain
 - Hot flashes



- **Helpful Hints**

- If you smoke, try to quit
- Cold drinks, cool fan in / near your face
- Avoid spicy foods
- Maintain healthy weight
- Sleep in a cool room, use cotton sheets
- Dress in layers, cotton if possible
- Limit alcohol and caffeine



- **Neuropathy**

- This may last months or even years in extreme cases.
- Take medications as prescribed.
- Physical therapy; acupuncture; exercise
- Take care handling sharp objects
- Test hot water temperature with thermometer
- Wear rubber-soled shoes
- Avoid trips, stumbles, and falls

- **Body changes and intimacy**

- Acknowledge changes and losses
- Talk with your partner as openly as you can
- Talk to your care team about physical changes that are happening
- Be patient... you may need to use some creativity with your partner to achieve a comfortable and intimate sex life
- Focus on the positive
- Be open to change
- Seek counseling and therapy, perhaps with your partner

- **Emotional Changes**

- Fear of completing treatment
- Sadness or a sense of loneliness; separation anxiety
- Loss of treatment friends / support system
- Adjusted value to life; not taking life for granted
- Seeking the “new normal”
- Fear of recurrence
- Talk with your care team
- Keep a journal of your feelings and reflections
- Maintain friendships with other patients
- Discuss your feelings with family, friends
- Continue with or join a support group
- Hopewell; SOS Program
- Remember that these feelings are not unusual
- Give yourself TIME to adjust



- **How to Manage Stress**

- Breathing exercises
- Prayer, quiet time
- Healing Therapies
- Yoga, Tai Chi
- Massage
- Laughter and joy
- Exercise
- Psychotherapy and possible medication

- **What is the “New Normal?” What might change?**

- Relationships with friends, family, coworkers
- Spiritual or religious beliefs
- Involvement in the community
- Work life, feelings about your career
- Your life in general



How to Bring New Meaning to Your Life

- Add humor, laughter, and love to your life whenever you can
- Enjoy funny things, children, pets; read uplifting stories
- Pray, meditate, use quiet time
- Volunteer in your community (hospital, church, school...)
- Celebrate milestones
- Surround yourself with uplifting family and friends
- Take time for yourself
- Find a fulfilling hobby – art, music, gardening, woodworking, etc.

Resources for Survivorship

Topic	URL
Advocacy	www.CancerAdvocacy.org
Cancer Care	www.CancerCare.org www.hopewellcancersupport.org phpa.dhmh.maryland.gov/cancer/cancerplan
Cancer Research	www.aicr.org
Cancer Screenings	stjosephtowson.com/cancerscreenings
Integrative Medicine	http://www.cim.umaryland.edu
Journaling	https://www.cancercare.org/publications/263-healing_with_words_journaling_and_reflecting_throughout_treatment https://www.cancercare.org/support_groups/89-healing_with_words_a_therapeutic_writing_group
Lymphedema	https://www.lymphnet.org
Survivorship	www.Cancer.Net/patient/survivorship www.CancerSurvivorsPlace.org http://livestrong.org http://survivorship.cancer.gov http://dccps.nci.nih.gov/ocs



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