

Uterine Cancer Survivorship Pamphlet

Before we discuss the recommendations for cancer surveillance as well as ways to manage potential side effects from treatment, let us first say congratulations! Undergoing treatment for uterine cancer is incredibly challenging. It requires bravery, perseverance, trust and strength. We want to take this time to honor you and all of the hard work, so again, congratulations!

Recommendations for Surveillance

Following the completion of your treatment, you will be monitored closely in clinic. Please see the table below for our uterine cancer surveillance recommendations.

	1-2 years after completing treatment	3-5 years after completing treatment	>5 years
Review of Symptoms and Physical Exam	Every 3 months	Every 6 months	Yearly
Pap smear	Not indicated	Not indicated	Not indicated
Imaging	Insufficient data to support routine use	Insufficient data to support routine use	Insufficient data to support routine use
Recurrence	CT scan or other	CT scan or other	CT scan or other
Suspected	imaging modality +/- CA-125	imaging modality +/- CA-125	imaging modality +/- CA-125

Salani, Surveillance for gynecologic cancers. Am J Obstet Gynecol 2011.

Please note that your provider may differ from these guidelines depending his or her clinical style and your unique history.

At these surveillance visits, we will be asking you about signs and symptoms of cancer recurrence. These include:

- vaginal bleeding
- new masses
- pelvic or abdominal pain
- bloating
- nausea
- vomiting
- changes to bowel and bladder habits
- decreased appetite and unintentional weight loss

If, at any time, you experience any of these symptoms or you feel that something is not right, it is imperative that you let us know.

We also recommend that you see your primary care doctor at least once a year. Your primary care provider will make sure that you are up to date with health care screenings including colonoscopies, mammograms, bone density scans, and other routine lab work.

Potential Adverse Side Effects and Management of those Side Effects

It is important to understand that not every woman will experience these side effects. If you do identify with any of these adverse side effects, please let us know so we can address them.

Most Common Surgical Side Effects:

Lymphedema (leg swelling)

- If your surgeon removed any lymph nodes during your surgery, you are at increased risk of
 lymphedema or leg swelling. Lymphedema occurs on the same side of the body as the lymph node
 dissection. It can present as heaviness, fatigue, or swelling in one leg. Please let us know as soon as
 possible if you believe you are suffering from lymphedema. Lymphedema, when detected and treated
 early, is reversible.
- If you are experiencing lymphedema, we recommend:
 - Referral to physical therapy
 - Compression garments
 - Manual lymphatic drainage
 - Water exercise
 - o Note: physical activity does not worsen or increase your risk of lymphedema

Surgical Menopause

Sudden onset of menopause, a drastic decrease in hormone levels, may occur if your ovaries were removed before you entered menopause naturally. Early or sudden menopause may also occur with chemotherapy and radiation therapy.

Signs and symptoms of menopause include:

- hot flashes
- night sweats
- vaginal dryness
- decreased libido
- sleep disturbance
- mood changes
- cognitive changes
- fatigue
- health conditions such as osteoporosis, cardiovascular disease and cognitive dysfunction

This exquisite drop in hormones can be very distressing for some survivors. Both holistic and pharmacologic interventions are used to help alleviate many of these side effects. Some recommendations for menopausal symptoms include:

- Acupuncture, meditation, exercise, yoga, black cohosh, weight loss and relaxation techniques.
- UCLA has an East-West Medicine Clinic with medical providers who specialize in combining Western
 medicine with Traditional Chinese medicine. These doctors are experts in acupuncture, body work,
 stress relief therapeutics and Chinese herbs. If you are interested, we are happy to place a referral for
 you. You can find more information about our East-West Medicine clinic at www.cewm.med.ucla.edu.

- If you do not find relief from these holistic treatments, antidepressants and other medications have been proven to improve hot flashes.
 - For vaginal dryness, we recommend using vaginal moisturizers three to four times a week at bedtime. There are many over the counter moisturizers. Our patients have had success with Luvena, Genneve and Coconut oil. We recommend water-based lubricants like K-Y Jelly or Astroglide during sexual activity.
 - In some cases, particularly with young survivors, it may be appropriate to consider hormone therapy. Please consult with your physician to see if you are a candidate for vaginal or systemic estrogen therapy.
 - o Proper sleep hygiene measures can help sleep disturbances. These include:
 - Maintaining a regular bedtime and waketime every day, daily physical activity, exposure to daily sunlight, avoiding alcohol and nicotine, limiting caffeine (particularly 4 hours prior to bed), ensuring your room is dark/quiet/cool and turning off electronics at bedtime.
 - If you are still struggling with insomnia, you may benefit from seeing a sleep specialist or consulting with your primary care provider or psychiatrist for further management options.
- Menopause increases your risk of osteoporosis, or bone thinning. We recommend a daily intake of 600
 International Units of Vitamin D, 1200 mg of Calcium and weight bearing exercises to decrease your
 risk of osteoporosis and bone fractures. If you do have osteoporosis, please follow up with your
 primary care provider for further management.

Dietary Reference Intakes: The Essential Guide to Nutrient Requirements. Otten JJ, Hellwig JP, Meyers LD (Eds), The National Academies Press, Washington, DC 2006. pp.530-541. Modified with permission from the National Academies Press, Copyright © 2006, National Academy of Sciences.

Sexual Concerns

- It is appropriate and understandable to have concerns regarding sexuality following surgery. Removal or treatment of any gynecologic organ can be a very vulnerable experience. We want to normalize and address your concerns.
- Please know that sexual activity cannot cause your cancer to recur, nor can you spread cancer to your partner through sexual activity.
- Following any kind of treatment for gynecologic cancers, women may experience painful sex, vaginal
 dryness, decreased libido or difficulty connecting to their sexuality or with intimacy.
- As discussed above, vaginal moisturizers and lubricants can be very helpful in decreasing vaginal dryness and decreasing pain during intercourse.
- Vaginal dilators and pelvic floor physical therapy are recommended for women who are experiencing painful sex. We have a vaginal dilator handout with more information as well as a list of pelvic floor physical therapists in our office. We can also refer you to our UCLA Rehabilitation Center for pelvic floor physical therapy. You can find more information on our Rehab center at www.uclahealth.org/rehab/
- If you are having trouble reconnecting to intimacy or sexuality, or are experiencing decreased libido, we recommend psychotherapy, sex therapy and couples therapy. We have a list of sex therapists in our office. Please inquire if interested.

Most Common Chemotherapy Side Effects:

Fatigue

- Fatigue is one of the most common complaints in cancer survivors. Fatigue is often worse in patients who undergo chemotherapy and/or radiation, however, cancer-related fatigue can also be experienced in women who are treated with surgery alone. Fatigue can last for months to years after a cancer diagnosis. It's important to be kind to yourself and to allow yourself the time you need to recover from your treatments. Fatigue can also be a symptom of depression, anxiety or other mental health conditions, so please let your cancer team know if you believe you are suffering from significant emotional distress.
- Strategies to improve fatigue include:
 - Daily exercise
 - Mental health therapy
 - Cancer support groups
 - Healthy, balanced diet
 - Acupuncture
 - Adequate sleep

Peripheral Neuropathy

- Peripheral neuropathy is defined as tingling, numbness or shooting pains in your fingers, toes or
 extremities. Neuropathy may begin during or after chemotherapy and results from damage to nerves.
 It does not occur with all chemotherapy agents. It is most common in women who receive the drug
 Paclitaxel. Neuropathy can range from being very mild to severe. You may notice that you have
 difficulty with fine motors skills such as buttoning your shirt, writing, typing or sometimes walking. For
 most survivors, neuropathy resolves and improves slowly over time. Unfortunately, for others,
 neuropathy may become a chronic condition.
- Treatments for neuropathy include:
 - Medications such as Gabapentin and Duloxetine
 - While the effectiveness of the following interventions have not been fully established, they have been shown to improve symptoms in patients:
 - Acupuncture, Vitamins such as Alpha Lipoic Acid, B vitamins, Glutamine, exercise, reflexology, cannabis and footbaths.

"Chemo-brain"

- "Chemo-brain" or cognitive dysfunction is a common side effect during and following chemotherapy. Some of these mental changes may include difficulty with short term memory, decreased concentration, difficulty multi-tasking and learning new skills. These cognitive changes often improve over time and do not progress to more serious conditions like dementia.
- Ways to manage cognitive dysfunction include:
 - Keeping a notebook or planner
 - o Daily exercise
 - Limiting alcohol use
 - Engaging in mindfulness activities including meditation, yoga and breath work exercises
 - Ensuring you are getting enough sleep

Most Common Long Term Radiation Side Effects:

Vaginal tightness and scarring

- Vaginal tightness and scarring are common side effects from pelvic radiation or brachytherapy. These adverse effects can lead to narrowing and shortening of the vagina. This can make sexual intercourse as well as in office pelvic exams painful and difficult to tolerate.
- It is important to understand that even if you are not sexually active or interested in being sexually active, pelvic exams are incredibly important in monitoring you for cancer recurrence. During exams, your provider will inspect the vagina and feel the pelvis for any concerning lesions or tumors. If the vagina becomes too shortened or scarred, these exams become less effective.
- Vaginal dilators are the primary treatment for vaginal scarring and tightness. We recommend using dilators three times weekly with a vaginal lubricant or moisturizer. We have a vaginal dilator handout in our office with more information.

A Survivor's Mental Health: Anxiety, Depression, Trauma and Distress

We hope that being a cancer survivor empowers you. We also understand that being a survivor places you at increased risk for mental health issues. It is normal and common to feel distressed, paranoid of recurrence, anxious, sad and generally different than how you felt prior to being diagnosed with cancer. Some of these feelings may subside with time as you integrate into your new normal. If you find, however, that these thoughts or feelings interfere with your ability to cope with or enjoy life, we recommend obtaining support from a mental health therapist and/or psychiatrist.

Please take advantage of UCLA's Simms Mann Center for Integrative Oncology, our cancer support center. Our Simms Mann Center provides free mental health resources for cancer survivors. If you are having trouble finding help, please let your cancer team know so we can assist you in finding you the care you need. If you ever feel like you want to hurt yourself or others, please let a loved one know and call 911. For more information about the UCLA Simms Mann Center for Integrative Oncology: www.simmsmanncenter.ucla.edu

Healthy Lifestyle

Maintaining a healthy lifestyle has been associated with improved quality of life, your overall well-being, and in some cases, a decreased risk in cancer recurrence and death. We understand that modifying longstanding behaviors can be hard. Please note that making even small changes can have a big impact on your health. Here are some recommendations to maintain a healthy lifestyle:

- Engage in physical activity every day. Consider taking the stairs, walking around the block or parking farther away from a store to increase your daily activity.
 - For cancer survivors, the NCCN recommends at least 150- 300 minutes of moderate-intensity per week and 75 minutes of vigorous-intensity per week. The NCCN defines moderate intensity as "can talk but not sing" and vigorous activity as "can say a few words without stopping to catch a breath."
 - Keep in mind that these are simply guidelines. Please listen to your body and discuss any concerns or limitations around physical activity with your primary care provider.
 - If you are suffering from peripheral neuropathy, consider aerobic exercise such as stationary biking or water aerobics. For resistance training, consider wearing padded gloves with free weights or resistance machines. Do not engage in any activity that does not feel safe.

- Avoid sitting for long periods of time.
- Eat a diet high in vegetables, fruits and whole grains. Avoid processed and excessively sugary foods.
- Limit alcohol intake to one drink/day for women.
- Stop using cigarette and tobacco products. Please let us know if you need resources to help quit smoking.
- Wear sunscreen daily, at least 30 SPF.
- Make sure you are getting enough sleep.
- Follow up with your primary care provider regularly to ensure you are up to date with all of your cancer screenings including colonoscopies and mammograms.
- Supplements are recommended for known deficiencies or conditions such as osteoporosis. We do not have data to suggest that the use of supplements or vitamins decreases your risk of recurrence. More important than supplements is eating a diet full of healthy nutrients.
- We encourage immunizations, such as the flu vaccine. If you are currently immunocompromised,
 please avoid any "live" vaccines such as the zoster vaccine. If you have just completed chemotherapy
 or radiation, it is preferred that you wait 3 months prior to receiving vaccines. If you have any
 questions regarding vaccines, please discuss this further with your cancer team and primary care
 provider.

Additional Resources

The UCLA Simms-Mann Center for Integrative Oncology: www.simmsmanncenter.ucla.edu

National Comprehensive Cancer Network: www.nccn.org

Cancer.net: www.cancer.net

American Cancer Society: www.cancer.org/healthy.html

USDA: www.choosemyplate.gov

How to Quit Smoking: www.cdc.gov/tobacco/campaign/tips/quit-smoking/index.html

Unless otherwise noted, the information in this packet is based on recommendations from the National Comprehensive Cancer Network's Survivorship Guidelines, Version 2.2020.



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