

Name: _____

MR#: _____

Survivor Summary

As a survivor, it is important that you keep a treatment summary and a copy of your care plan. You may want to create a file that also includes your healthcare provider's information and current medications (Visit www.oncolink.org/oncopilot for forms you can use to organize this material). While some survivors continue to see an oncologist or specialized survivorship provider, many return to a primary care provider or internist for routine care, many of whom are uncertain how to care for you. Developing the care plan can help you and your medical team understand what issues to look for, and how to handle them.

The list below can be used to track the recommended follow up care based on your treatments. You should use these as a guide to your cancer follow up care and discuss further with your physician.

You received the following treatments for Rhabdomyosarcoma

- Cyclophosphamide (Cytoxan®, Neosar®)
- Dactinomycin (Cosmegen®)
- Vincristine (Oncovin®, VCR)
- Radiation to the pelvis
- X-ray based radiation- IMRT

Risks Related to Medications

Risk of Bladder or Urinary Tract Toxicities

Key Takeaways

- Avoid alcohol and smoking.
- Tell your healthcare provider if you have any of the following symptoms:
 - Pain when urinating.
 - Urinary hesitancy (difficulty starting the stream).
 - Urinary urgency or frequency.
 - Getting up in the middle of the night to urinate.
 - Blood in your urine.

Risk of Developing Bladder Cancer

Key Takeaways

- Avoid alcohol and smoking.
- Report the following symptoms to your healthcare provider:

- Pain when urinating.
- Urinary hesitancy (difficulty starting the stream).
- Urinary urgency or frequency.
- Getting up in the middle of the night to urinate.
- Blood in your urine.

Peripheral Neuropathy

Key Takeaways

- Peripheral neuropathy is caused by irritation or damage to nerves, leading to feelings of numbness, “pins and needles,” tingling, burning, or a feeling of weakness or heaviness in the arms or legs.
- Peripheral neuropathy can be a long-lasting side effect that can require physical therapy, changes in your daily life for safety, and managing pain with medication.

Risk of Developing Osteoporosis

Key Takeaways

- You should avoid smoking, caffeine, and excessive alcohol intake.
- Perform weight bearing and strength training exercises 2-3 times per week.
- Aim for a Calcium intake of 1000-1200mg per day plus Vitamin D 800iu to 1000iu per day (ideally from food sources, and supplements when your diet is not sufficient).
- Consider screening for osteoporosis with a DEXA scan.

Raynaud's Phenomenon

Key Takeaways

- Raynaud's phenomenon is a condition that causes blood vessels in certain areas of the body to constrict or spasm, causing numbness and cold feeling in that area.
- Avoid smoking and medications that constrict blood vessels.
- Protect affected areas from cold exposure.
- Have your blood pressure checked every year.

Skin Toxicities

Key Takeaways

- Care for your skin with mild soaps and hydrating lotions.
- Protect your skin from sun damage.

Learning Differences

Key Takeaways

- Let your healthcare team know if you have trouble with short term memory, multi-tasking, new learning, reading comprehension, working with numbers, or a decrease in concentration that is affecting your day-to-day life.

Fertility Concerns for Female Survivors

Key Takeaways

- Survivors wishing to become pregnant should consider seeing a fertility specialist familiar with cancer survivors.
- All women should use protection when sexually active if pregnancy is not desired, and to protect against sexually transmitted infections.

Risk of Developing a Secondary Cancer

Key Takeaways

- There is a small risk of developing leukemia, myelodysplastic syndrome, lymphoma or other cancer years after your treatment is completed.
- The risk is higher in the first 10 years after your treatment.
- Report the following symptoms to your healthcare provider promptly:
 - feeling more tired or weaker than usual
 - looking pale
 - shortness of breath
 - loss of appetite
 - weight loss
 - chills, fevers, night sweats
 - painless swelling of a lymph node
 - easy bruising, nose bleeds, or bleeding from the gums
 - pain in your bones
- Consider having a complete blood count with differential checked by your healthcare provider if you experience any of the above symptoms.

Understanding New Research and Therapies

Key Takeaways

- Many cancer treatments today have not been available long enough to determine what effects they may cause in years after treatment.
- Always let your healthcare team know if you notice any new or worsening symptoms.

Remember, you know your body best.

- Periodically look for new information about your treatment and talk to your healthcare team to see if they have anything new to report.

Side Effects of Radiation

Key Takeaways

- Protect your skin from the sun by seeking out shade, using sunscreen, and not using tanning booths.
- Report any changes in moles, skin lesions, bone pain, or lumps found in the radiation treatment area.

Bone Health

Key Takeaways

- If you experience any kind of trauma involving the area that received radiation (for example, a fall), you should be seen by a provider to be sure you have no broken bones.
- Physical/ Occupational therapy can be helpful for managing arthritis.
- Non-steroidal inflammatory medicines can also be helpful for managing arthritis.
- You may need to see an orthopedic doctor or physical/occupational therapy if your limbs are not the same length and it is affecting function.
- If your spine was in the treatment field, it should be examined every year until you have stopped growing.

Maintaining Healthy Skin

Key Takeaways

- You should wear sunscreen (SPF 30 or higher) anytime you are outdoors.
- You should see a wound care specialist or surgeon if you have any skin wound or ulcer that does not heal.

Bowel Health

Key Takeaways

- See a provider right away if you have severe abdominal pain, especially if you also have nausea/vomiting and constipation or if you are bleeding from the rectum or have dark (black) stools.
- Anti-diarrheal medicines can be helpful for chronic diarrhea.
- You should see a dietitian if you have unintended weight loss.
- A screening colonoscopy is recommended for all people beginning at age 45. For those who

received abdominal radiation, screening colonoscopy is recommended beginning 10 years after radiation therapy or at age 35, whichever is later, with repeat colonoscopy every 5 years.

Female Pelvis

Key Takeaways

- The use of personal lubricants and/ or vitamin E can help if the vaginal area is painful, dry, or tender during intercourse.
- Vaginal dilators should be used to help keep the vagina open.
- Talk with your provider about treatment for vulvar pain.
- A physical therapist can help with managing the swelling of genitals or legs.
- You should see a high-risk pregnancy specialist if you wish to become pregnant.
- You should see an endocrinologist if you do not go through puberty by age 13, or if you have a change in menstrual patterns or symptoms of menopause after treatment.
- You should have a bone density evaluation if you have any deficiencies in ovarian hormones.

Lymph Nodes

Key Takeaways

- Radiation to an area increases the risk of lymphedema. You should see a Certified Lymphedema Therapist at the first sign of swelling.
- You should be taught how to care for the area and to notify your healthcare team if there are any signs of infection. You can learn about self-care on [OncoLink](#).
- If you develop swelling, numbness, tingling, pain or loss of strength in the treated area, tell your healthcare provider.

Bladder Health

Key Takeaways

- Report any new or worsening bladder symptoms to your provider.
- Avoid alcohol use and smoking because these can further irritate your bladder.

Taking Care of Your Health After Cancer

Key Takeaways

- Vaccines are an important part of staying healthy. Follow your care team's recommendations for vaccines.
- The HPV vaccine reduces the risk of HPV-related cancers and is recommended for all survivors.
- Participate in cancer screenings recommended for your age and history.

A Note on Fatigue

Key Takeaways

- Make sure that fatigue is not being caused by another problem. Find ways to cope and manage the fatigue. Regular exercise, acceptance, and reprioritizing will help.
- Alert your healthcare provider if fatigue is worsening or a new symptom so they can evaluate this.
- Get regular exercise to help combat fatigue.

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