

Healthcare Provider Summary

Dear Healthcare Professional

A survivorship care plan was created for or by your patient using the Smart ALACC care plan tool at www.smartalacc.oncolink.org. This report is a summary of the long-term side effects the survivor may be at risk for and recommendations for their follow-up care. The report is generated from the treatment information entered by the patient or their healthcare provider. The summary provided is supported by cancer survivorship literature and expert opinion, but should not replace communication with the patient's oncology team. Suggested management and follow-up points are broken down according to the toxicity-causing treatment (i.e. medical therapy, surgery, or radiation).

Keep in mind that survivors should continue to have screening for other cancers per the American Cancer Society guidelines and routine health maintenance as recommended by the USPTF.

You received the following treatments for Rhabdomyosarcoma

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

Follow Up Care for Rhabdomyosarcoma

Each pediatric cancer survivor is unique given the many subtypes of cancers, personalized treatments, and how treatments were tolerated. A survivorship care plan is meant to help you and your patient navigate their needs as they transition away from regular oncology visits. The oncology team will provide more information about needed follow up testing protocols.

Risks Related to Medications

Risk of Bladder or Urinary Tract Toxicities

- Risks after high-dose cyclophosphamide include hemorrhagic cystitis and decreased bladder capacity, as well as development of bladder cancer.
- Evaluate for concerning urinary symptoms with urinalysis, urine culture, and urology referral.
- Encourage patients to avoid alcohol and smoking.

Risk of Developing Bladder Cancer

- Encourage smoking and alcohol cessation.
- Patients who also received radiation to the pelvis are at increased risk.

- Assess for urinary symptoms at least annually; obtain urinalysis and urine culture for symptomatic patients; and obtain renal/bladder ultrasound and urology referral for patients with culture-negative microscopic or macroscopic hematuria.

Peripheral Neuropathy

- Peripheral neuropathy is a side effect that develops during or shortly after treatment but can become a chronic problem for some survivors.
- It does not develop as a late effect and if a survivor does develop symptoms suggestive of neuropathy after therapy, other causes should be investigated.
- Assess for any limitations/safety hazards due to toxicity.
- Pain management with tricyclic antidepressants, gabapentin, and pregabalin. Refer to pain specialist for pain that is not well managed.
- Refer for physical/occupational therapy for symptomatic neuropathy and assessment of hand function.

Risk of Developing Osteoporosis

- Long term use of corticosteroids, receiving chemotherapy medications, radiation to weight-bearing bones, hormone therapy, gastrectomy, and orchiectomy all increase the risk of developing osteoporosis.
- Calcium intake of 1000-1200mg per day plus Vitamin D 800iu to 1000iu per day (ideally from food sources, and supplements when the diet is not sufficient).
- Encourage smoking cessation and minimal or no caffeine or alcohol intake.
- Promote a healthy lifestyle with a good diet and weight-bearing and strength training exercise 2-3 times per week.
- Consider screening with a DEXA scan.

Raynaud's Phenomenon

- Monitor blood pressure annually.
- Counsel on factors that exacerbate Raynaud's (cold, vasoconstrictors such as pseudoephedrine and stimulants, cocaine, and nicotine)
- Avoid prescribing vasoconstrictors.
- Encourage smoking cessation.

Skin Toxicities

- Encourage patients to:
 - Use a mild soap and water for washing.
 - Use a hydrating cream or lotion for dry or scaly skin.
 - Keep nails trimmed to avoid them ripping. Do not use fake nails or gel manicures as these can further damage your nails.
 - Protect skin from the sun.
 - Have good hygiene and skin care.
 - Evaluate for any signs of infection or non-healing skin wounds.

Learning Differences

- Neurocognitive changes as a result of cancer therapy may include difficulty with short term memory,

multi-tasking, new learning, reading comprehension, working with numbers and a decrease in concentration ability.

- Cancer survivors should be screened annually with attention to educational/vocational progress.
- Referral to a survivorship program or for neurocognitive testing and cognitive rehab may be of value for survivors with cognitive symptoms.
- Evaluate for treatable causes such as hypothyroidism, depression, or anxiety.

Fertility Concerns for Female Survivors

- Due to cancer treatments, survivors may have sexual health and/or fertility issues after treatment.
- Refer to a reproductive specialist (endocrinology or gynecology), experienced in working with cancer survivors, for signs of ovarian hormone deficiency and/or fertility assessment.
- Pregnant survivors should consider being followed by a high-risk obstetrician.
- Survivors should be aware of the need for contraception and that recovery of fertility may occur years after therapy.
- Bone density evaluation is recommended in patients with estrogen deficiency.

Risk of Developing a Secondary Cancer

- Certain chemotherapy agents or radiation can lead to the development of leukemia, MDS, or lymphoma. This typically occurs 4-10 years after therapy, but could occur as soon as 1-3 years after therapy (early onset is most common with etoposide or teniposide).
- Evidence shows little benefit of sending screening CBCs in the absence of clinical signs/symptoms. Obtain a CBC with differential for concerning signs and symptoms.

Understanding New Research and Therapies

- Many cancer treatments today have not been available long enough to determine what effects they may cause in years after treatment.
- Evaluate for any new or worsening symptoms that may be unexplained by other factors.

Side Effects of Radiation

Long term effects of radiation therapy differ based on the areas of the body that were exposed to radiation, the location and size of the radiation field, as well as the type of radiation and the radiation techniques that were used.

There is a chance of developing a tumor (either cancerous or non-cancerous) in the area that was treated with radiation. Cancers can develop in the skin, bone, or other tissues in the area.

- Examine skin in the radiation field for any changes, lesions, bone pain, or masses.

Bone Health

- Radiation can increase the risk of bone fractures. Joints in the treatment field can develop permanent stiffness, pain, and arthritis.
- Rapid evaluation for fracture after trauma.
- Yearly spinal assessment for scoliosis/kyphosis until growth is complete.
- Physical or occupational therapy and NSAIDs for arthritis.

Maintaining Healthy Skin

- Skin is more sun-sensitive after radiation. Counsel to use sunscreen diligently.
- Evaluation by a wound care specialist for any non-healing ulcers.
- Skin can develop chronic swelling, wounds, changes in texture and color.

Bowel Health

- Survivors are at risk for scarring and strictures, ulceration and bleeding, chronic diarrhea and poor absorption, and fistula formation.
- Immediate medical evaluation for severe abdominal pain, bleeding from the rectum, dark stools or abnormal passage of urine or stools.
- Use anti-diarrheal medicines for chronic diarrhea.
- Consult a dietitian for weight loss or nutritional deficits.
- Screening colonoscopy or DNA stool testing at age 45 for all patients.
 - For those who received abdominal radiation: screening colonoscopy beginning 10 years after radiation therapy (or at age 35, whichever is later), with repeat colonoscopy every 5 years. For patients unable to undergo colonoscopy, and multitarget stool DNA test every 3 years is a reasonable alternative.

Female Pelvis

- Tanner staging yearly until sexually mature, with referral to gynecology for any girl or young woman who has no signs of puberty by age 13, has a failure of pubertal progression, abnormal menstrual patterns, or menopausal symptoms.
- Use of personal lubricants and/ or vitamin E if the vaginal area is painful, dry, or tender during intercourse.
- Use of vaginal dilators for scarring that caused a decrease in the size of the vagina. Evaluation by gynecology if the insertion of dilators or tampons is difficult.
- Psychologic support and medicines such as tricyclic antidepressants for treatment of vulvar pain syndromes.
- Physical therapy and lymphedema education for swelling of genital or legs.
- Evaluation by high-risk pregnancy specialist for survivors who wish to become pregnant. Testing for ovarian function may include FSH and estradiol levels, as well as anti-Mullerian hormone levels. A uterine evaluation may include ultrasound prior to pregnancy.
- Evaluation by an endocrinologist for hormonal abnormalities and/ or premature menopause. Women with low hormone levels should have annual bone density screening.

Lymph Nodes

- Radiation increases the risk of lymphedema over surgery alone. A Certified Lymphedema Therapist should be consulted at the first sign of swelling for best outcomes.
- Survivors should be educated about self-care and to notify the healthcare team with any signs of infection. Instructions for survivors on risk reduction can be found at OncoLink: <https://bit.ly/3cgcgqz>
- Radiation and/or surgery can damage nerves, which can be further aggravated by scar formation and result in neuropathic pain. Survivors with this pain may benefit from seeing a pain specialist.

Bladder Health

- Radiation that includes the bladder can lead to fibrosis, hemorrhagic cystitis, neurogenic bladder, bladder cancer, and make the survivor more susceptible to UTIs.
- Counsel to avoid alcohol and tobacco use.

A Note on Fatigue

- Evaluate any new or worsening fatigue.
- Encourage regular exercise to help combat fatigue.

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