



Survivorship Care Plan

This plan is designed to help those who have been treated for Hodgkin lymphoma in planning long-term management and appropriate monitoring, ideally in collaboration with the physicians who have cared for them. Please read the appendix at the end of the plan, which explains how best to use it.

My Details

Name:

Date of birth:

Diagnosis: Hodgkin lymphoma

Date of diagnosis:

Staging (include B symptoms, such as fever without infection, drenching night sweats and unplanned weight loss):

My Treatment: Summary to Date and Latest Response

Did you receive radiation therapy? If so, provide the dates, dose and site of treatment:

Did you receive chemotherapy? If so, provide the dates, medications you received and the cumulative dose of anthracycline, if administered (dose x number of cycles):

Did you receive other treatments, such as immunotherapy? If so, provide the dates, medications you received and number of cycles:

What has been your response to the treatment(s) you received? Complete, partial, stable, or is your disease progressing?

What about your family history? Do you have a genetic predisposition to heart disease or cancer?

A Healthy Lifestyle: the Basics

The following five items are strongly suggested for all cancer survivors. They are known to reduce your risk of complications or long-term effects.

Healthy diet

Regular physical activity/exercise

Not smoking and drinking alcohol only within advised limits

Reach and maintain a healthy weight

Maintain psychological and spiritual wellbeing

Potential Ongoing Treatment Toxicities and/or Late Effects

This is the all-important list that should create awareness for anyone who has been diagnosed and treated for Hodgkin lymphoma.

• **Cardiovascular Disease** – This is a common late effect for HL survivors, so preventive care is essential.

Anthracyclines, many of which have drug names ending in *rubicin*, and radiation therapy may place you at high risk for late effects.

Have your blood pressure screened at least once a year to ensure you do not have hypertension.

Lipid screening (a blood test that measures your cholesterol and triglycerides) is recommended beginning at age 20 or after completion of treatment because of the higher risk of heart disease. Consider repeating lipid screening every 1-3 years.

Echocardiogram, used to check the overall health of your heart, should be considered at the end of treatment, one year after treatment and then at appropriate intervals (every 3-5 years) if you received either radiation to the heart area or anthracycline treatment.

A stress test, which is used to check how your heart reacts to physical activity, should be considered 5-10 years post-treatment if you received radiation therapy.

Carotid artery imaging (or other type of vascular imaging) should be considered 5-10 years post-treatment if your neck received radiation therapy. This is typically performed as an ultrasound scan.

• Sun Safety

Because patients are at risk for skin damage up to 2 years post-treatment, use high-quality sunscreen (SPF 30 or higher) on sun-exposed skin.

Be aware that, over time, you remain at increased risk for developing skin cancer in the areas that received radiation therapy.

• Infection Risk

NOTE: We recommend that individuals who have been diagnosed with Hodgkin lymphoma **not receive** live vaccines. The Covid-19 vaccines are fine; they are **not** live vaccines.

Be sure to request an annual **inactivated** influenza vaccination.

If your spleen has been surgically removed or has received radiation, you are at increased risk for certain infections and should have the following vaccinations: meningococcal, Haemophilus influenza type B and pneumococcal pneumonia. You hopefully can have all three at the time of treatment; if not, it is advised that you have them later. Pneumococcal pneumonia vaccinations should be repeated every 5 years.

If you have received a stem hematopoietic cell transplant, you should have meningococcal, Haemophilus influenza type B and pneumococcal pneumonia vaccinations, as well as tetanus, diphtheria and hepatitis B, polio and measles/mumps/rubella vaccinations.

• Secondary Cancers

Skin cancer is a risk after radiation therapy. It is recommended that you self-monitor your skin carefully and consider seeing a dermatologist periodically.

Breast cancer is a risk, especially in women treated with chest or axillary (armpit) radiation between 10-30 years of age. Self-examination is recommended beginning during puberty, followed by annual mammograms beginning at age 25 or 8 years post-treatment, whichever occurs later. Annual breast MRI exams may also be considered starting at the same time.

Colorectal cancer is a risk if you were treated with pelvic, abdominal or spinal radiation. Colonoscopy screening may be recommended 10 years post-treatment, with subsequent follow-up depending on initial findings. Certain chemotherapy drugs also may increase the risk of gastrointestinal cancers. You are encouraged to participate in national cancer screening programs; your physician can help with this.

Lung cancer is a risk if you were treated with radiation therapy to your chest. Smoking cessation and ongoing awareness are important.

• Pulmonary (Lung) Disease

This is a risk if you were treated with bleomycin. Radiation therapy can also cause fibrosis to the lungs (see below).

• Endocrine Disorders

Endocrine disorders result when disease or treatment affects the complex system of hormones needed to maintain health.

Thyroid disorders are a risk if you were treated with radiation therapy to your neck. You are advised to have an annual blood test to check your thyroid function, along with a physical examination of your neck.

Infertility may occur as a result of treatment. If so, consider seeing a reproductive specialist.

Premature menopause may occur after chemotherapy or radiation therapy to the abdomen or if you had surgery to move your ovaries before you received radiation therapy.

Osteoporosis risk can be increased, especially if you experience early menopause or if steroids were part of your treatment. Screening is recommended (a DEXA scan) at the onset of menopause and then every 5-10 years. A calcium-rich diet, vitamin D supplements and weight-bearing exercise are recommended for all. Careful consideration should be given to the use of hormone replacement therapy (HRT) if you are at increased risk for breast cancer.

- **Psychosocial Problems**

These are quite common following treatment for any cancer, including Hodgkin lymphoma. Screening for depression and anxiety should be considered at all office visits, with support and treatment offered as needed.

- **Radiation Fibrosis Syndrome (RFS)**

This condition can affect any structure passing through an area that has received radiation therapy, potentially causing problems due to muscle wasting and weakness. Nerve damage also may cause pain or weakness.

- **Dry Mouth**

This condition may occur following radiation therapy to the salivary glands, which are located in the mouth and jaw area, or after receiving chemotherapy. Taking saliva substitutes may help, and dental checkups and good hygiene are especially important because reduced salivary flow can lead to dental decay.

- **Peripheral Neuropathy**

This condition affects the nerves and can produce pain, numbness and weakness. You may be at risk if you received certain chemotherapy medications, especially vincristine.

- **Fatigue**

Fatigue is a well-recognized problem long-term after treatment for cancer. Seek help to manage this if simply pacing yourself does not help restore your energy.

- **Graft-versus-host Disease**

After treatment for Hodgkin lymphoma, you are at risk for graft-versus-host disease—where the immune system attacks healthy tissue—so it is important that the blood products you subsequently receive be treated with radiation. Your physician will advise you if you should have blood products that have been treated in this way.

Special Notes

Please include here any additional information on your health, your treatment and your current condition that may be helpful to communicate to your physicians.

Appendix: How to Use This Care Plan

This care plan reflects the existing guidelines in the U.S., U.K. and throughout Europe and is designed to assist you in having productive conversations with your physicians and other clinicians about planning your care. At this point, there is no international consensus on how to best manage Hodgkin lymphoma. Because it is a relatively rare diagnosis, many individuals may not be fully aware of the relevant health concerns.

Our hope is that you will print out or download this document, add your details and share it with your physicians. The information is intended to inform both you and them of the best information we have about caring for you over the course of your lifetime. The goal of Hodgkin's International is to help improve the quality of life of those who have been treated for HL. Having a care plan can help you receive the long-term, follow-up care and relief of late effects that you need.