



Survivorship Plan

This proforma is designed to help survivors of treatment for Hodgkin Lymphoma to plan their long-term management and any appropriate surveillance, preferably in conjunction with the doctors who have care for them, or who have treated them in the past. It has been drawn together to support the aims of the charity Hodgkin's International, which include "supporting long-term follow-up care and relief of late effects". **Please read the appendix** at the foot of the form about how the form has been drawn up, and how best to use it.

DETAILS OF INDIVIDUAL

Name

Date of birth:

Diagnosis: Hodgkin Lymphoma

Date of diagnosis:

Staging (B symptoms present?):

If **radiotherapy** given, dates, dose and site of treatment:

If **chemotherapy** given, dates and agents used and cumulative anthracycline dose if used (dose x number of cycles)

Other treatments, such as immunotherapy, used

Response to treatments: Complete/ Partial/ Stable disease/ Progressive disease

SUMMARY OF TREATMENT TO DATE AND LATEST RESPONSE ASSESSMENT

HEALTHY LIFESTYLE

This is strongly advised for all survivors of cancer. It can reduce your risks of complications or long-term effects.

- Healthy diet
- Regular physical activity
- Not smoking and drinking alcohol only within advised limits
- Reach and maintain a healthy weight
- Look after your psychological and spiritual wellbeing

POSSIBLE ONGOING TREATMENT TOXICITIES AND/OR LATE EFFECTS WITH RECOMMENDED FOLLOW-UP

- Cardiovascular Disease**
 - **Anthracyclines**, eg drug names ending -rubicin, and **radiation** may place you at risk of this
 - You should have your **blood pressure** monitored, ideally annually
 - **Lipid screening** recommended at age 20, or after completion of treatment and consider repeat 3 yearly
 - **Echocardiogram** should be considered at 10 year and then suitable intervals (3-5 years) if you had radiation to the heart area, or received anthracycline treatment
 - A **stress test** should be considered after 10 years if you received radiation
 - **Carotid artery imaging** could be considered at 10 years if your neck received radiation, or other vascular imaging if appropriate in irradiated areas, usually as an ultrasound scan.
- Sun Safety**
 - Patients are at risk of skin damage up to 2 years post treatment. Patients should wear high quality SPF 30 on sun exposed skin
 - Longer term you remain at increased risk in areas that received radiation treatment
- Infection Risk**
 - **WE DO NOT RECOMMEND LIVE VACCINES FOR PATIENTS WITH/POST HODGKIN LYMPHOMA**

- You should request annual inactivated **influenza** vaccination
- If you have had **splenectomy or splenic irradiation** then you are at increased risk of certain infections and it is recommended that you have **Meningococcal, Haemophilus influenza type B** and **Pneumococcal** vaccinations: preferably you will have had all three at the time of treatment, but if not then it is advised to have them later. Pneumococcal protection should be repeated every 5 years.
- If you have had **haematopoietic stem cells** then you too should have **Meningococcal, Haemophilus influenza type B** and **Pneumococcal** vaccinations, and also in addition **tetanus, diphtheria** and **hepatitis B, polio and measles/mumps/rubella** vaccinations
- **Secondary Cancers**
 - **Skin cancer** is a risk after **radiation** treatment
 - **Breast cancer especially in women treated with chest or axillary radiation between ages 10-30. Self-examination** (“breast awareness”) is recommended from puberty onwards and then annual **mammograms** starting at age 25 or 8 years after treatment, whichever occurs later; annual **breast MRI** may also be considered starting at the same time.
 - **Colorectal cancer if treated with pelvic, abdominal or spinal radiation. Colonoscopy** may be recommended 10 years after treatment, subsequent follow-up dependent on initial findings. Some chemotherapy drugs may also increase the risk of gastrointestinal cancers. You **are recommended to take part in national cancer screening programmes.**
 - **Lung cancer if treated with chest radiation.** Smoking cessation and awareness are important.

POSSIBLE ONGOING TREATMENT TOXICITIES AND/OR LATE EFFECTS WITH RECOMMENDED FOLLOW-UP (continued)

- **Pulmonary (lung) disease**
 - This is especially a risk if treated with **bleomycin. Radiation** can also cause fibrosis to lungs.
- **Endocrine disorders**
 - **Thyroid** disorders if treated with **neck irradiation**: annual blood test for thyroid function, and physical examination are advised.
 - **Infertility** is a problem for some after treatment, and referral to reproductive specialist is advised
 - **Premature menopause** can follow **chemotherapy or radiotherapy** to the abdomen, or if you had surgery to move your ovaries before radiotherapy.
 - **Osteoporosis** risk can be increased especially if there is early menopause or if steroids were part of your treatment. Screening is recommended (DEXA scan) at onset of menopause in women and then every 5-10 years. Calcium rich diet, Vitamin D supplementation and weight-bearing exercise recommended for all. Careful consideration should be given to use of HRT (hormone replacement therapy) if you are also at increased risk of breast cancer.
- **Psychosocial issues** are quite common following treatment for any cancer, including HL. Screening for depression and anxiety should be considered at any review, and support and treatment offered as appropriate.
- **Radiation Fibrosis Syndrome (RFS)** can affect any structure passing through an area that has been irradiated. This can cause problems due to muscle wasting and weakness and nerve damage may also cause pain or weakness.
- **Dry mouth** can follow **radiation to the salivary glands** in the neck or **chemotherapy**. Saliva substitutes can be used. Dental checks and good hygiene are especially important due to the increased risk of **dental decay** with reduced salivary flow.
- **Peripheral neuropathy** is an increased risk after some chemotherapy especially vincristine.

- **Fatigue** is a well recognised problem long term after treatment for cancer. Help may be available with managing this, and you may need to consider pacing yourself.
- **Irradiated blood products** should if possible be used as there is a lifelong increased risk of Graft versus Host Disease following HL. Your medical team will be able to advise you if you should have irradiated blood products.

SPECIAL NOTES

Appendix: important information about how to use this plan

This care plan has been developed taking account of existing guidelines from the USA, UK and Europe and with advice from the Oncology Department in Oxford (UK). The evidence is quite sparse for how best to manage long term effects and risks associated with a diagnosis of Hodgkin Lymphoma and subsequent treatment. Therefore, the strategy has been to develop sensible recommendations. These are designed to help you have conversations with your doctors and health care professionals about planning your care. As Hodgkin Lymphoma is quite rare, many of these people may not know much about the relevant issues.

This document is for you to download, add your details, and then share with your doctors. It is to inform both you and them of the best information that we have about caring for you into the future, to enable those conversations, and to give some weight to them such that even the less well-informed healthcare worker may be able to see why you need this plan in place. I truly hope that it will succeed helping to improve the quality of life for many people, by improving long-term follow-up care and relief of late effects, in line with our organization’s objectives.

January 2021