

Personal care plan Lymphoma patient

Providing support for patients and their families

This is a personal care plan to help you get involved in your own care by helping you to think about the things that are important to you in managing your LYMPHOMA.

| | |
|---------------------------------|---|
| Name | |
| What I like to be called | |
| Hospital Number | |
| KEY WORKER | Hom Ramkelawon Macmillan Lymphoma Nurse Specialist |

at the Royal Sussex County Hospital

What is a care plan?

It is a written agreement between you and your **KEY WORKER** to help you manage your health day-to-day.

What is a Named Key Worker for cancer patients?

Cancer care is complex; spanning many health and social care settings and often requires the involvement of those working in primary, secondary and tertiary care together with those in statutory and voluntary organisations.

For many years cancer services, have been required to have a process in place to ensure effective cooperation of care between all professionals involved in the management of cancer patients. Many Department of Health recommendations emphasises on the need to identify a 'key worker' for each individual patient to achieve a smooth coordination.

A KEY WORKER is define as 'a person who, with the patient's consent and agreement, takes a key role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice' (NICE 2004).

What does a Care Plan involve?

Creating the care plan will involve a conversation with your key worker about the kind of support you might need now and in the future. The aim of a care plan is to organise the support around you, so that you feel confident about looking after yourself as much as you possibly can.

You have been allocated a key worker who will work with you to draw your care plan based on your choices and if you would like more explanation please discuss with your key worker:

Hom Ramkelawon – Macmillan Lymphoma Nurse Specialist
Telephone: 01273 696955 Ext. 3807

Cancer treatment decisions:

Fill in these 4 boxes to help you decide

Set your ground rules

Decide how much you want to know

Decide how you want to make your treatment decisions

Have realistic expectations

Accept help

Decide on goal

Cure

Control

Comfort

Analyse the benefits versus the risks

Side effects

How treatment affects your life

Your health in general

Communicate with your family and treating team

Doctor name

Chemo nurse name

Other

Understand my
disease

Prognosis

Treatment
choices

My blood
and
investigations
test results

Holidays

Work or
college

Food
and
Drink

Changing
treatment

Money or
benefits

My other health
concerns

Future care
planning

Family and
relationship

You will be invited for a care planning meeting.
Before your care planning meeting, please take some time to think about what you would like to discuss and then note this down on the page provided.

| I would like to talk about | Date |
|----------------------------|------|
| | |
| | |
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| | |

Please bring your medication list to the care planning meeting.

My Care Plan

Your care plan will be completed with you at your care planning meeting. It will list the things that are currently important to you in your care and that of the future. It might include notes about things that are currently working well and things that you want to keep the same. It might also take into account things that you want to change and goals that you and your team would like to work towards. Below are some of the questions you might like to consider regarding your care before your care plan meeting.

Issue or concern:

Can I bring someone with me?

How would I like things to be different?

What do I need to do?

What might help me?

What might stop me?

What do I need my care team to do?

Review date:

Following your care planning meeting with your specialist nurse please spend some time considering the following questions to make sure you have made the right choice in your 'Personal Care Plan'.

Please circle your answer.

AM I SURE?

Do you feel sure about the best choice for you?

Yes

No

DO I UNDERSTAND?

Do you know the benefits and risks of each option?

Yes

No

WHAT ARE MY PRIORITIES?

Are you sure about which benefits and risks matter most to you?

Yes

No

DO I NEED HELP MAKING A CHOICE?

Do you have enough support and advice to make a choice?

Yes

No

What does working in partnership mean?

Working in partnership with health professionals means that they're not always the ones who make the decisions. You'll be in charge and take some of the responsibility that comes with day-to-day self-management. That way you can make a big difference to your health and your life.

How long does a care plan last?

As your life changes over time, your needs will change. So your care plan needs to be flexible and adapted to your changing needs. You should have a conversation about care options, including self-care support, at least once a year, when your care plan is reviewed or more often if you choose.

Your key worker will:

- Provide a point of contact for the patient
- Assess, develop and where appropriate, provide individualised holistic care and support to the patient. The key worker is also responsible for monitoring and evaluating their care.
- Co-ordinates the patient journey ensuring interventions take place and communicated to the patient in a timely fashion. The provision of timely and individualised information enabling patients / carers to make informed choices about their current and future health / care needs
- Answer your questions and offer written information about your cancer, investigations, treatments or symptoms
- Ensure the investigative process runs smoothly and efficiently
- Offer emotional and practical support and advice
- Help you to understand any symptoms or side effects of treatment
- Assess your needs to address any ongoing concerns
- Signpost and get information on how to address financial worries
- Act as the patient's advocate e.g. represents the patient's views / concerns at the MDT.

The Multidisciplinary Team:

In line with National Guidelines, decisions on the best way to treat your disease will involve a range of knowledgeable professionals meeting together to discuss treatment options.

This is called a Multi-Disciplinary Team (MDT) meeting. Your case will be discussed by a group of consultant haematologists and consultant clinical oncologist with an interest in Lymphoma.

There will be expert review of your diagnosis by specialist haematology pathologists and radiologists specialising in haematological cancer will review your scans/radiology.

When all this information has been gathered, which can sometimes take time, there will be a joint discussion of your case to determine your best treatment options.

Your CNS is at all MDTs to represent the patient's views and may feed back the discussion to you if you want them to or the need arises.

The Haematology MDT Meeting is held on every Monday morning except on bank holidays.

Psychological support

Psychological distress is a natural response to being diagnosed with a serious illness.

People can respond to this distress in different ways.

They may get support from family and friends or from other sources such as nurses and doctors.

Some patients however find this is not enough and would benefit from professional support from a trained psychological support professionals.

Cancer patients are advised to seek psychological support.

This is available and can be arranged for you by your CNS or by other professionals who care for you.

Likewise you self refer by calling:

Macmillan Psychological Therapies Team

Sussex Cancer Centre

Royal Sussex County Hospital

Telephone **01273 664694**

if no one is free to take your call please leave a message on the answer phone.

Social support

People affected by illness can have a variety of needs in terms of social support, ranging from practical help at home through to local care services. This can be arranged through the hospital or by your G.P., whichever is most appropriate.

Financial advice

Money is often a major concern for people facing illness. Your CNS can help by giving you contact information about financial entitlements that may be available and can also help with form filling if needed. It is best to think about this early on in your treatment.

Get in touch with B&H CAB Welfare Benefits Service at the Sussex Cancer Centre on **01273 223955**
Or email macmillan@moneyadviceplus.com

Spiritual Support

The hospital provides a Chaplaincy Service. As well as the main religions, The Chaplain team is able to provide contact details for perhaps less well known ones. However spirituality is not necessarily confined to religious matters but also unsettling questions such as 'Why is this happening to me?' and 'How will I cope?' often arise. Your CNS can to organise this.

LYMPHOMA

Your Disease is called

The Staging of your disease is

Staging is a system of categorizing an individual's disease into one of four groups which give a general idea of how far the disease has spread. This is done after a series of tests are conducted to determine which parts of your body are affected by lymphoma.

The Grading of your disease is

Lymphomas are either Hodgkin lymphoma (Hodgkin's disease) or Non-Hodgkin lymphoma. NHL can be fast growing (high grade) or slow growing (low grade).

Imaging investigations

X-rays: can be used to look at various parts of your body. For example, a chest X-ray may be used to see if there are any enlarged lymph nodes in your chest.

CT scans: Computed tomography (CT) scans use a series of X-rays to create pictures of your body in cross-section, like 'slices' through your body.

MRI scans: Magnetic resonance imaging (MRI) scans are similar to CT scans, except it uses strong magnets instead of X-rays

PET scans: Positron-emission tomography (PET) scans give more detailed information about cell activity. They are particularly good for helping doctors work out which cells are cancerous and which are not.

PET/CT is the combination of both the PET Scan and a CT Scan.

Ultrasound Guided Biopsy: The Ultrasound scanner uses high frequency sound waves that reflect back off solid body parts to make an image to guide a needle to remove a sample of tissue for examination.

Core Biopsy: In this procedure a larger tissue sample is taken for examination. You may have local anaesthetic injection and sometime a stitch.

About your treatment INTENTIONS

Watch and Wait

If watch and wait is recommended for you, it means you have a slow-growing form of lymphoma and:

- you are well and you have no troublesome symptoms from your lymphoma
- you have small lymph nodes that are not causing problems or is not growing rapidly
- your blood tests are at acceptable levels
- none of your major organs (heart, lungs, kidneys) are affected.

It means active treatment will be kept in reserve until:

- your symptoms become troublesome
- your enlarged nodes start to change markedly, or
- test results suggest that your major organs or bone marrow are no longer working well.

Curative

The goal is to treat patients with intention to cure.

Palliative

Palliative care (also called supportive care) is treatment aimed at relieving symptoms. Its main purpose is to improve your quality of life. It's often given along with cancer treatment, but may be also used when cancer treatment is no longer working.

Treatment outcomes

Treatment with **Curative Intent** can have different outcomes.

Remission

means your lymphoma has been controlled following treatment.

There are different degrees of remission:

CR – Complete remission means there is no visible evidence of your lymphoma.

PR – Partial remission means your lymphoma has been reduced remarkably. Sometimes doctors talk of 'good partial remissions' or even 'very good partial remissions' to describe more precisely the degree of response to treatment.

Relapse means your disease has come back after being in remission or has flared up after a quiet period.

Refractory means that the lymphoma is resistant to the treatment given.

Chemo / Radiotherapy:

No. of Cycles / Fractions:

Mid Treatment Imaging:

Comments:

| Cycle 1 | Date | Date |
|-----------------------|------|------|
| | | |
| Cycle 2 | | |
| | | |
| Mid treatment imaging | | |
| | | |
| Cycle 3 | | |
| | | |
| Cycle 4 | | |
| | | |
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| | | |

Holistic Needs Assessment

Physical Problem

Appearance, breathing, constipation, diarrhoea, appetite

Fatigue, memory / concentration, nausea/vomiting, pain

Sexual concerns, dry skin / itching, sleep, tingling sensation

Practical Problem

Care of children / relative, housing, money, transport, work

Family Problems

Relationship with partner / children

Emotional Problems

Worry, sadness, anger, guilt, depression, nervousness

Spiritual Problem

Loss of faith, loss of meaning or purpose in life

One copy of the Holistic Needs Assessment is included with this booklet. Please feel free to fill it while you would be in the middle or at the end of your treatment. You are advised to contact your key worker for more details.

Free Prescriptions for Cancer Patients

Criteria:

Exemption certificates will be issued to those applicants

BELOW 60 years old and who in their doctor's judgement are receiving treatment for cancer, the effects of cancer,

or

the effects of current or previous cancer patients.

For more detail YOUR KEY WORKER

Cancer Information Prescription

What is Cancer Information Prescription?

An Information Prescription (IP) provides personalised health and medical information about a patient's diagnosis, treatment and care plan. It should broadly cover the key points in the discussions they've had with their doctor, nurse or other health carer.

Information prescriptions have been developed by the NHS in England to improve information given to people with cancer.

Where can I find the information?

Information Prescription Service on the NHS Choices website to create this prescription. This library of information is produced by the NHS and other specialist organisations, including Cancer Research UK.

How will Cancer Information Prescriptions help me?

Most people using the system will be nurses. The public can access the Information Prescription Service directly through NHS Choices.

Research

You may receive information on available research for clinical trials, which you could be involved with.

Entry into trials is voluntary and a decision not to enter a trial will not prejudice your clinical care.

The trial nurses will be available to discuss these treatment options with you.

Your care and treatment

We will respect your privacy and dignity.

We will be sensitive to and respect your religious, spiritual and cultural needs at all times.

What to do if I become unwell?

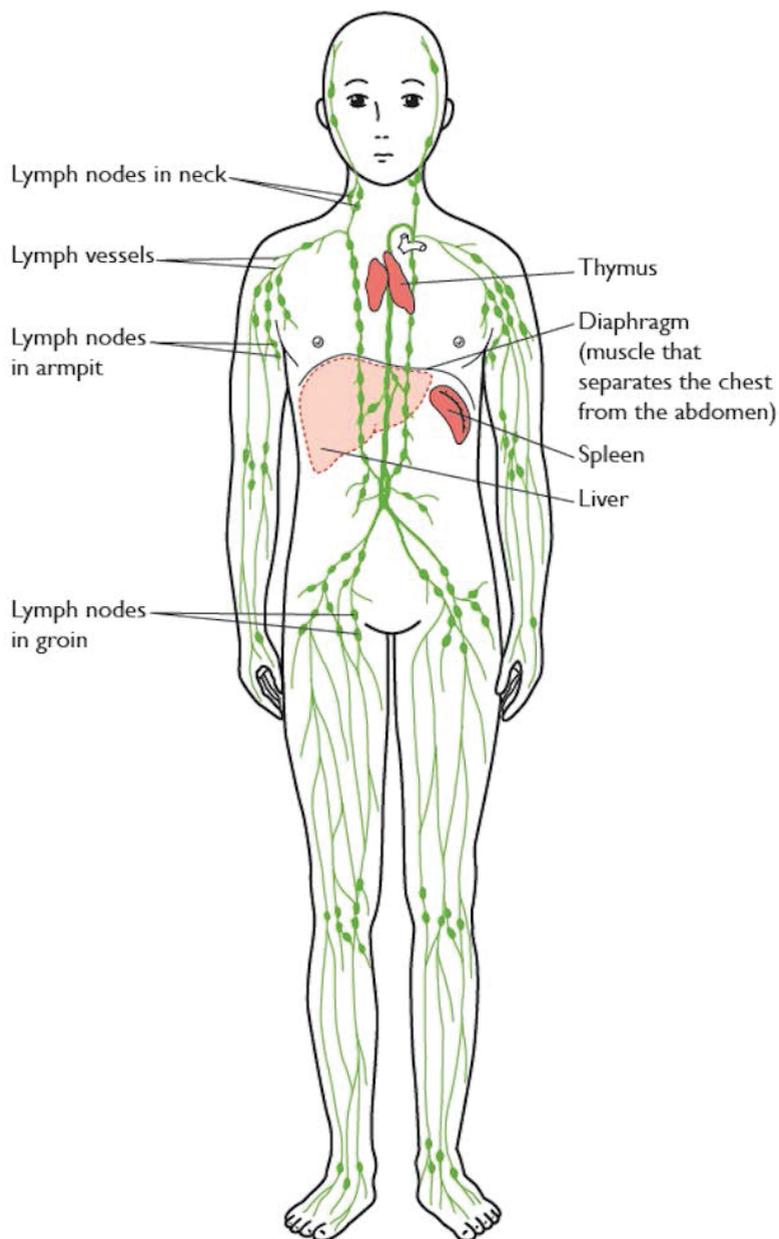
Your treatment may well become quite complex; if you become unwell or develop new symptoms **we would like you to contact us in the first instance**, as your GP may not be in the best position to deal with your problem.

At the start of your treatment we will tell you the sort of symptoms to look out for.

You will be given a contact card **(RED CARD)** listing the best way to contact us at any time and in case of **EMERGENCY**.

Otherwise call your CNS if you are in doubt.

The lymphatic system



Surviving cancer

Surviving cancer or 'survivorship' can be defined in different ways.

Two common definitions include:

- Having no disease after the completion of treatment
- The process of living with, though, and beyond cancer. By this definition, cancer survivorship begins at diagnosis. It includes people who continue to have treatment to either reduce risk of recurrence or to manage chronic disease.

Common symptoms and problem areas in cancer survivors

(This list is non-exhaustive and symptoms are treatment related.)
Late effects symptoms

| General | Oral health | Psychological Problems | | Physical Symptoms |
|--|---|--|--|-------------------|
| Fatigue and Insomnia Socio-economic difficulties (finance / work / housing) | Dental Problems Dryness of Mouth | Insecure (fear of recurrence) Anxiety Depression | | |
| Sexual Health | Diet / Intestinal Track | Pain | Blood Counts | |
| Erectile Dysfunction Loss of Libido Poor Lubrication | Loss Appetite Loss sense of taste Constipation Diarrhoea | Neuropathic pain Visceral pain Somatic pain | Anaemia Low immunity (High risk of contracting some common infections) Low Platelets (High risk of bleeding) | |

Keeping Track of Your Care

(A detailed medical history of your lymphoma)

- Type of lymphoma
- Date of diagnosis
- A list of the types of treatment you received, including drug names and doses; and the location and doses of radiation therapy given
- Pathology reports
- Copies of imaging studies, including X-rays, CT scans, PET scans, etc.
- Any treatment complications
- Types of side affects you experienced
- A list of the possible late effects of your treatment
- Your doctor's recommendations for frequency of follow up visits.

Brighton Lymphoma Patients Support Group

Meeting every last Friday of the month from 5 to 7 pm.
Sussex House, Abbey Road, RSCH, BN2 1ES.

PRH LYMPHOMA PATIENTS SUPPORT GROUP

(Contact your key worker for more details)

The Lymphoma Association

<https://www.lymphomas.org.uk>

FREEPHONE HELPLINE **0808 808 5555**

The Macmillan Support

<http://www.macmillan.org.uk>

FREEPHONE HELPLINE **0808 808 0000**

Sussex Cancer Network

Telephone **01273 696955**

Reception **Ext. 4324**

Chemo Suite **Ext. 7950**

Radiotherapy Reception **Ext. 4901**

PET scan **Ext. 4572**

MRI **Ext. 4665**

Nuclear Med **Ext. 4382**

CT scan **Ext. 4926**

Haematology-Oncology Day Care Unit

Level 9, Sussex Renal Building

Telephone **01273 696955 Ext. 7413**

If you do not understand this leaflet, we can arrange for an interpreter.

إذا كنت لا تستطيع فهم محتويات هذه النشرة فبإمكاننا عمل الترتيبات لتوفير مترجم شفوي لك.

এই প্রচারপুস্তিকাটি যদি আপনি বুঝতে না পারেন, তবে আপনার জন্য আমরা একজন অনুবাদকের ব্যবস্থা করে দিতে পারি

如你不明白本單張的內容，我們可安排口譯員服務。

如你不明白本傳單的內容，我們可安排口譯員服務。

اگر مندرجات این جزوه را نمیفهمید، ما می‌توانیم مترجم در اختیارتان بگذاریم.

Jeśli masz trudności w zrozumieniu tej ulotki, możemy zorganizować tłumacza.

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Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

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