

Your Guide to Personalised Cancer Care

NHS

North Central London

Cancer Alliance

North Central London Health and Care

Integrated Care System

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Introduction

Getting a cancer diagnosis can feel overwhelming and frightening. You may be worried about how treatment will affect different aspects of your life, such as your family, work or money.

The North Central London Cancer Alliance (NCLCA) is working with local hospitals and other care providers to ensure that you get the care and support that is right for you. This is called personalised cancer care. It means that your cancer care will meet your individual needs and will focus on what matters to you.

This booklet complements information you will have received from your cancer team about your diagnosis, treatment and helpful contact details. The booklet explains the help you can expect from NHS and support services to meet your needs and directs you to useful resources.

What is Personalised Cancer Care?

As soon as you are diagnosed with cancer you should receive care and treatment that takes into account your individual concerns, needs and circumstances, and which supports you to live as well as possible throughout your treatment.

You will work with your medical team and other professionals to make the right choices for you and build your knowledge and confidence in managing your care.

There are 5 key aspects to personalised cancer care:

1. Personalised care and support planning
2. End of Treatment Summary
3. Health and well-being information and support
4. Cancer Care Review
5. Quality of Life Survey

1. Personalised care and support planning – based on Holistic Needs Assessment

So that your team understands what is important to you, your clinical nurse specialist (CNS) or another member of the team should offer you an assessment of your needs. This is called a Holistic Needs Assessment (HNA) and will be offered to you very soon after you receive your diagnosis.

It will be reviewed at other important points, such as when you have finished treatment or your needs change. The assessment may be completed face to

face, over the telephone, or through a link sent to you online.

The HNA looks at different areas that may be causing you concern from your physical health, to emotional, social, financial or other practical concerns. You are guided to think about what matters most to you and how you might find support to address these concerns.

Once you have identified any concerns, a member of the team will talk through these and come up with a care plan with you to address these. This will include links to information and services, and linking you to referrals where appropriate. You will also be provided with important contact details, and an allocated key worker throughout your treatment.

2. End of Treatment Summary

When you reach the end of a period of treatment, you should receive an End of Treatment Summary.

The End of Treatment Summary will include:

- Your diagnosis, including the stage of your cancer, and key test results
- Details of the treatment you received
- Details of any follow-up arrangements

- Possible medium and long-term side effects or complications
- Concerning signs and symptoms to tell your GP or cancer team
- Details of who to contact, and how, if you need support or have any concerns.

A copy of your treatment summary should also be sent to your GP surgery. You may wish to take along or send your own copy to the GP surgery in case they don't receive it.

3. Health and well-being information and support

In addition to medical treatment, information and support is available to provide extra help for you.

Including:

- Emotional support
- Managing side effects
- General physical well-being
- Money, finance and benefits advice
- Managing returning to work
- Making healthy lifestyle choices

It is important that you get all the support you need to live as well as possible during and after treatment. Other sources of information and support are available, which a member of your team can direct you to.

4. Cancer Care Review

Within 3 months of your diagnosis your GP surgery should contact you (by phone or letter) to offer to discuss any support you may need.

A Cancer Care Review should also be offered to you through your GP surgery. This is usually within 12 months of your diagnosis with a GP or practice nurse.

This review should include:

- A discussion of your diagnosis, current needs and your concerns
- Extra support you might need
- A review of your medications
- Referral or signposting to help you to access other services, such as rehabilitation, counselling, or other voluntary or community organisations, known as social prescribing.

If you have concerns at any point during or after your cancer treatment you can always contact your GP surgery.

5. Quality of Life Survey

The Cancer Quality of Life Survey is a national NHS survey. It is for people in England who have had a cancer diagnosis. You will be invited to complete the survey around 18 months after diagnosis.

The aim of the survey is to find out how your quality of life may have changed after diagnosis. We want to see where care is working well or not so well, and if any new services are needed. To do this, we are asking people who have experienced cancer how they are feeling. We then compare their answers with information about their cancer diagnosis and treatment. This will help us to improve the way we support you to live as long and as well as possible.

What to expect – timeline

Please note: If you find you haven't received one or all of these interventions during your cancer pathway, please contact the appropriate clinician or the organisation in **bold**.

Diagnosis

Personalised Care and Support Plan – based on Holistic needs assessment

Carried out by a **Cancer Nurse Specialist (CNS), Allied Health Professional (AHP) or Cancer Support Worker.**

You and your GP surgery should be given a copy of this care plan.

Contact from GP surgery

Invitation and information sharing letter or phone call taking place in the first **3 months following** your diagnosis.

Treatment

End of Treatment summary

Created by your cancer team and sent to **you and your GP surgery** following a Treatment Review.

Personalised Care and Support Plan – based on Holistic needs assessment

Carried out by a **Cancer Nurse Specialist (CNS), Allied Health Professional (AHP) or Cancer Support Worker.**

You and your GP surgery should be given a copy of this care plan.

Living with and beyond cancer

Cancer care review

Carried out by a **GP or a practice nurse** taking place in the first **12 months following your diagnosis.**

Cancer quality of life survey

Sent **electronically or in a letter from NHS England**, 18 months after initial diagnosis.

At the end of the survey you will receive a patient summary of needs which you can share with your GP surgery team.

Health and Wellbeing information and support

This is verbal or written information and signposting, or invitations to wellbeing education webinars or support groups.

It is provided throughout your cancer pathway by your cancer team, GP surgery or cancer information centre.

You can find a wide range of support services in your local area by visiting www.cancercaremap.org

(Timeline chart developed by: South East London Cancer Alliance)

Follow-up arrangements

After your treatment you may be offered different options for follow-up. This may include an option known as Patient Initiated follow-up.

PIFU is designed to reduce the number of outpatient appointments you need to attend after your treatment has ended.

If this type of follow-up is suitable for you, your clinical team will let you know, and you may be offered:

- Regular surveillance scans and/or tests, with quicker and easier access to results. It is important to attend these scans and tests.
- Quick access to your cancer team, including telephone advice and support, if you are concerned about any symptoms, side-effects, or treatment.
- Information about signs and symptoms that could indicate your cancer has returned.
- Personalised care and support to self-manage and improve your health and well-being.

Alternatively, depending on your own needs, you may be invited to follow-up appointments with a doctor or clinical nurse specialist (CNS) or someone from the multidisciplinary team.

Cancer information and support at local hospitals

Macmillan Cancer Information Centres provide a relaxed and informal confidential and free drop-in service to patients, family and friends affected by

cancer. The teams offer emotional support, financial and practical advice that is right for the individual.

University College London Hospitals NHS Trust

Living Room, located on the ground floor, University College Hospital Macmillan Cancer Centre

address: Huntley Street, London, WC1E 6AG

tel: 020 3456 7890

hours: Monday to Friday, 9 am to 5 pm (last drop-in session at 4.45 pm)

email: uclh.supportandinformation@nhs.net

North Middlesex University Hospital

Main atrium, level 0, between main reception and outpatients.

address: Sterling Way, London, N18 1QX

tel: 0208 887 3992

hours: Monday to Friday, 10 am to 4 pm (closed 12.30-13.30, and bank holidays)

email: northmid.cancerinfo@nhs.net

Royal Free London NHS Foundation Trust

Barnet Hospital

Located inside the main entrance on level 1.

address: Wellhouse Lane, Barnet, EN5 3DJ

tel: 020 8216 4142

hours: Monday to Friday, 9 am to 5 pm (last drop-in session at 4.45 pm)

email: rf-tr.BCFCancerInfo@nhs.net

Chase Farm Hospital

Located on the ground floor, between the two entrances of the main building.

address: The Ridegeway, Enfield, EN2 8JL

tel: 020 8375 2247

hours: Monday to Friday, 10 am to 4 pm (excluding bank holidays)

email: rf-tr.BCFCancerInfo@nhs.net

Royal Free Hospital

Located on the ground floor oncology outpatient department.

address: Pond Street, London, NW3 2QG

tel: 020 7794 0500 ext. 31337

hours: Tuesday to Friday, 10 am to 4 pm

email: rf.cancerinfo@nhs.net

There is also a **Maggie's Centre** at the Royal Free Hospital, supporting NCL patients, family and friends through the emotional and practical challenges cancer can bring.

address: Royal Free Hospital, Pond Street, London, NW3 2QG

tel: 020 3981 4840

hours: Monday to Friday, 9 am to 5 pm

email: royalfree@maggies.org

Whittington Health NHS Trust

Located on the ground floor of hospital, just inside the main entrance.

address: Magdala Ave, London, N19 5NF

tel: 020 7288 5305 or 07881 834 433

hours: Monday to Friday, 10 am to 4 pm (excluding bank holidays)

email: whh-tr.cancerinfowhitthealth@nhs.net

Support and Information

Your Cancer Pathway Support Guide

Your online or printed guide to key questions to ask when you are referred for tests to investigate for cancer, or if you have already been diagnosed with cancer.

cancersupportguide.nclcanceralliance.nhs.uk

Cancer Wellbeing London

Cancer health and wellbeing information, activities and seminars run by the NHS in your area. There are short videos providing advice on common concerns and there are links to the major cancer charities.

www.cancerwellbeinglondon.nhs.uk

Cancer Care Map

This is an online directory that helps people find cancer care and support services in their local area.

www.cancercaremap.org

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

tel: 111

www.111.nhs.uk

NHS Live Well

Advice, tips and tools to help you make the best choices about your health and wellbeing.

www.nhs.uk/live-well

Cancer52

Information, advice, and signposting, to relevant resources and organisations for rare and less common cancers.

tel: 020 3355 1989

www.cancer52.org.uk

North Central London Cancer Alliance

Details of how cancer services are being improved and joined up across north central London, plus links to information and support, and ways you can get involved as a patient.

How can I share my experience?

Your clinical team

If you want more information about personalised care or you have not received something described in this resource, talk to your clinical nurse specialist. If you do not feel comfortable doing this, call the cancer information centre for your hospital who will help you get the support you need.

Patient Partner involvement

If you would like to help us develop and improve cancer services across North Central London, we would love to hear from you! Please get in touch.

tel: 07929 069134

email: uclh.nclcanceralliance@nhs.net

National Cancer Patient Experience Survey

This asks questions about your experiences throughout your cancer treatment. The results are used to make improvements to cancer services. This is sent to some people with cancer each year. If you get one, please consider completing this to give honest feedback about your experiences.

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Our thanks to Guy's and St Thomas' NHS Foundation Trust and North East London Cancer Alliance for some of the information in this booklet.