

# Your Local Cancer Services



An information booklet  
for patients with cancer

## Leicester Cancer Centre

Edition 12: April 2022  
For review: April 2024

# The Macmillan Information and Support Centre



The Macmillan Information and Support Centre provides information about cancer, and offers information on practical help and advice to anyone affected by a diagnosis of cancer, their families and carers.



Staff in the Macmillan Information and Support Centre will provide you with the information you need, or signpost you to help and support available locally and nationally.

This is a drop-in service and there is no need to make an appointment.

We also offer a video call service. This is an opportunity to speak to one of our Macmillan Information and Support Officers online via a video link. Please contact us on the details below.

## **Opening hours are 9:30 to 4:30 Monday to Friday**

The Macmillan Information and Support Centre is located in:

Osborne Building, Leicester Royal Infirmary

**Tel: 0116 258 6189**

**email: [cancerinfo@uhl-tr.nhs.uk](mailto:cancerinfo@uhl-tr.nhs.uk)**

**Website: [www.leicestershospitals.nhs.uk/cancerinfo](http://www.leicestershospitals.nhs.uk/cancerinfo)**

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# Introduction



## **This booklet is for all patients with cancer and their carers**

This booklet has been designed to help you understand the support services in place for you and your family whilst having cancer treatment. It gives a broad outline of treatments offered and gives you information about the health care team involved in your care. In addition, it lists the support services, including voluntary agencies that are available.

Similar information is also available on the LLR Cancer Support App.

The app is designed for people living with and beyond cancer in Leicester, Leicestershire and Rutland. Search for “LLR Cancer Information” in the app store.

This booklet and the app will be updated on a regular basis. If you have any recommendations on how they can be improved, or wish to order more copies of the booklet, please contact the Macmillan Information and Support Centre.


We hope you find this booklet useful.

**Dr Helen Brooks**  
**Cancer Centre Clinical Lead**

**Jane Pickard**  
**Macmillan Lead Cancer Nurse**

# The people who will care for you

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The Cancer Centre at the University Hospital of Leicester NHS Trust is not a single building, but is made up of coordinated services to provide high quality cancer care across the whole Trust. The services are spread across the three main hospitals in Leicester, working together with colleagues in general practice, through our commissioners (the clinical commissioning groups or CCGs). It is possible to be treated at more than one hospital, because some tests and treatments may only be available at one site.

## **Treatment at the hospitals**

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As a patient with cancer you are under the care of a specialist consultant. Your consultant is a member of a team of experts in the treatment of your particular type of cancer. Sometimes the type of care you need will change, for example from surgery to drug treatment (or the other way round). The specialist consultants are all experts in their area, so it may be necessary to transfer your lead consultant from one consultant to another to make sure you always receive the best possible care.

We understand the importance of having a point of contact and a real person you know and trust to talk to openly about your concerns, even if you do need different specialists to treat you along the way. We aim to provide this through your cancer nurse specialist (key worker) wherever possible (see overleaf).

You may be treated as an in-patient or a day-patient, or you may be seen in the out-patient clinic. Which members of the healthcare team you see will depend on where you are treated and what you are being treated for.



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## **Your cancer nurse specialist (key worker)**

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Your key worker will make sure you understand what is happening, when and why. When you are told your diagnosis, you will be offered the opportunity to meet with a Cancer Nurse Specialist (CNS). The CNS will be your key worker and you will be given their contact details.

In some circumstances there may not be a CNS available. Please ask your consultant or a member of the nursing team if you are not told who your key worker is.

## **The multidisciplinary team (MDT)**

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The team of health professionals looking after you is known as the multidisciplinary team, or MDT. The multidisciplinary team meets to discuss the most appropriate treatment for you. A member of the team will then discuss your treatment plan with you.

The MDT meeting ensures that the treatment recommended to you has been individually tailored to your situation and needs, and has been checked by many experts to make certain that the care we are giving you is the best available.

## **Treatment at home**

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When you are at home your doctor (GP) will be in contact with your consultant, and can arrange for district nurses, community nurse specialists and other health professionals to help with your care, if needed.



The MDT (see above) will make sure your GP is fully aware of your individual treatment plan, so that they are able to support you through your treatment for cancer.

### **Healthcare professionals who may be involved in your care are:**

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**A consultant** - the doctor in charge of your care, an experienced specialist in his or her field. He or she leads a team of doctors looking after you, but all of them work closely with your consultant to give you the expert care you need.

Whoever you see at your clinic appointment, you can be sure that your care has been carefully considered and tailored not just to your cancer but to you by a team of experts.

The types of specialist who will be looking after you either in person or behind the scenes are;

**An oncologist** - a doctor who specialises in the treatment of cancer with drugs or X-rays.

**A radiologist** - a doctor who understands and interprets any scans or x-rays you have had. They mainly help in discovering cancer in the first place and in working out whether, and how far, it has spread. This information will allow your doctors to recommend the best treatments for you.

**A histopathologist** – you may have had a biopsy taken, where a sample of tissue is removed for examination. A histopathologist will look at the biopsy under a microscope to decide if cancer is present and if so what sort of cancer you have. This information is vital in deciding what treatment is best for you.



**A cancer nurse specialist (key worker or CNS)** - can provide support, advice and information about your cancer. He or she can explain the treatments available to you and can discuss any concerns you may have. Your CNS will act as a link between you and the rest of the team, continuing to support you before, during and after your treatment. Your key worker will offer you a Holistic Needs Assessment so that you can identify any needs that you might have.


**A cancer support worker** - works closely with your key worker. They may meet with you or provide telephone advice and will always make sure your key worker or CNS is aware of any support you may require. They may help you complete a holistic needs assessment or concerns checklist so that you can have a care plan which is individual to your needs.

**A therapy radiographer** - organises and gives radiotherapy treatment. He or she works closely with your oncologist to plan and deliver the right treatment for you. X-ray treatment for cancers can be incredibly effective at either curing the cancer, or alleviating symptoms.

**A dietitian** - is able to give you appropriate advice about how to get the best from your diet, and will assist with any eating problems you may have. If you have any dietary concerns please ask your doctor or specialist nurse to refer you to the dietitian.

**An occupational therapist** – offers practical and psychological support to help you to adapt to any changes in your lifestyle due to your illness.





**A physiotherapist** – assesses and treats you to help you maintain an independent lifestyle if you have any disability due to your illness.

**A district nurse** - visits you in your own home, to give you treatment and nursing care.

**Medical and nursing students** learn by being involved in the treatment and care of patients. Every fully trained doctor and nurse was once a student and learned from patients in the past. However, if you do not wish students to be involved in your care, please let a member of your healthcare team know. You have a right to privacy.

No one will be offended and it will not affect your care.

**Other health professionals may be involved in your care, for example:**

- ward nurses
- out-patient nurses
- chemotherapy nurses
- healthcare assistants
- chaplains
- social workers
- speech and language therapists

## **Confidentiality**

All NHS staff are under a legal duty to keep information about you confidential. Information will not be given to your relatives or carers unless you agree to this. There are a few exceptions to this rule; for more information please ask to speak to a member of the medical or nursing staff.

## Types of treatment you may be offered

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As there are many different types of cancer, so there are many forms of treatment. The main forms of treatment are surgery, radiotherapy, chemotherapy and immunotherapy.

Depending on your type of cancer, you may receive one or a combination of these treatments. Your treatments will be planned in the MDT meeting (see page 6), and they will be based on your individual needs. They will be set out in a “treatment plan” and this will be discussed with you so that you understand and agree to it. This is important, as before any treatment starts you will need to sign a form to say that you consent to the proposed treatment.

### **Surgery**


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You may be offered surgery. This may involve an operation to explore, or remove, all or part of the cancer. This will usually require you to be admitted to hospital. To help you make your decision, the recommended treatment will be discussed with you in detail. You will be told what the surgery will involve, and will have a chance to ask questions.

### **Radiotherapy**

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Radiotherapy (sometimes called X-ray therapy) is the use of high energy radiation to kill diseased cells in the body. It can be used to treat several diseases, the main one being cancer.



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All the cells in the part of the body being treated will be affected by the radiation, but only the diseased ones will be destroyed. The healthy ones will soon recover.

The treatment is totally painless (just like having an ordinary X-ray) and can last anything from a few seconds to several minutes.

Radiotherapy treatment can be used to cure cancers and reduce the chance of a cancer coming back. It is also used to reduce cancer symptoms.

Many people with cancer will have radiotherapy as part of their treatment. This can be given either as external radiotherapy, from outside the body using x-rays, or from within the body as internal radiotherapy.


The equipment used for radiotherapy is very specialised, and there is only one department in Leicestershire and Rutland that gives this treatment. This is in the Osborne Building at the Leicester Royal Infirmary.

## **Chemotherapy**

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Chemotherapy is treatment with drugs (cytotoxic drugs) that destroy cancer cells. These drugs may be given as injections, drips, tablets or capsules.

Sometimes this involves a hospital stay, but most chemotherapy is given to you as an out-patient on the Chemotherapy Suite. How often you have the treatment will depend on the drugs you require.



Chemotherapy can cause side effects, for example nausea or sickness. If this happens there are medicines available that can help to reduce some of these effects.

If you are offered chemotherapy treatment, you will be given more information. This will tell you more about all aspects of chemotherapy and your particular treatment. You will be told how often you will have the treatment, and any possible side effects will be explained.

At the present time the majority of chemotherapy is given at the Leicester Royal Infirmary, where there are the facilities and the appropriately trained staff needed to give this treatment.

### **Immunotherapy**

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Immunotherapy drugs boost the body's immune system to fight cancer cells. If you are being offered immunotherapy, you will receive more information about the specific drug.

### **Other treatments and investigations**

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Depending on your illness you may need other treatments or investigations. These could include:

- blood transfusions
- physiotherapy
- X-rays and scans
- other drug therapies

Some diseases need certain treatments. For example, some blood disorders require bone marrow transplants.

Separate leaflets are available for most treatments and investigations. If you would like further information please contact the Macmillan Information and Support Centre.

**Tel: 0116 258 6189**

### **Clinical Trials and Research**

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There are many different cancer clinical trials and research going on at the University Hospitals of Leicester NHS Trust (UHL). If you are interested in finding out how you can become involved or to find out more about taking part speak to your health care team.

If a suitable trial or research study is available, you may be invited to take part. This means that you could have the opportunity to be given a new treatment or you may be asked to provide information to help your health care team understand your cancer. You will receive a full explanation about trials or a research study you consider and be provided with written information. Taking part in research is voluntary, so you can choose whether or not to be involved, you can withdraw at any time and any information about you is confidential.



# Complementary therapies



## Complementary therapies

There are a growing number of therapies that may improve your general wellbeing and quality of life, for example:

- yoga
- aromatherapy
- reflexology
- acupuncture

Please ask a member of the team looking after you about the safety and availability of these treatments.

You may have to pay for some of these treatments, as they are not always available on the NHS. However, Sue Young Cancer Centre (see page 23) and LOROS (see page 24) provide some complementary therapies free of charge for patients with cancer and their families.

It is essential to talk to your doctor before using any complementary therapies.

## Getting the help and support you need at home

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If you are finding it difficult to look after yourself at home, and need assistance with your day-to-day activities, you can ask for help from Social Care Services. They may be able to provide different types of assistance according to your needs. This may range from information to assessment of needs and provision of care or equipment, whether in your own home or in a care home. Ask your cancer nurse specialist (key worker) for more information.

Social care services are arranged by your local council, and they aim to meet the needs of people from all communities. You may have a financial assessment for some aspects of care and may need to pay, or contribute to, the cost of your care.



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## **Accessing Social Care Services**

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### **In hospital:**

If you have been finding it difficult to manage at home, please speak to your nurse, who can refer you to an occupational therapist (OT). The OT can discuss with you and your family how you have been coping and what your problems are. The OT can complete an assessment and arrange for equipment to be delivered to your home before you are discharged.

### **At home:**

Contact your local Social Care Services using the telephone numbers below. They can arrange for you to be assessed at home so that a plan of care can be agreed.

### **Residential and nursing homes:**

A small number of people cannot continue to live in their own homes. Social Care Services may assist people to choose the right residential or nursing home. They can also offer advice about financial assistance with fees.

### **How to contact Social Care Services**

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You can contact the Social Care Services Department using the relevant telephone numbers below:

<b>Leicester (City)</b>	<b>0116 454 1004</b>
<b>Leicestershire (County)</b>	<b>0116 305 0004</b>
<b>Rutland</b>	<b>01572 722 577</b>



## NHS Continuing Healthcare (CHC)



NHS continuing healthcare is for individuals whose main or primary needs are health-related. People who are eligible are likely to have complex health needs that require a lot of care and support from health care professionals.

Before arranging a package of care, or care home placement, through social care services all patients should have an NHS continuing healthcare checklist completed. This will determine whether they need an assessment to find out whether or not they are eligible for care funded entirely by the NHS.

Anyone assessed as having a certain level of care needs may receive NHS continuing healthcare. It is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided.

If your needs have changed following a stay in hospital and you are unable to return home with your existing level of care package the ward team will refer you to the Discharge Coordination Hub using a Home First needs assessment form. The team will be able to advise you about the best place for you based on your health and care needs. The team always try to aim to get you home first if at all possible. Longer term assessments in respect of CHC funding will be undertaken following discharge in the home environment. If you are in hospital and are concerned about your discharge speak to a member of ward staff about this. If you are at home, speak to your community nurse.



Please refer to the Department of Health information booklet "NHS Continuing Healthcare and NHS-funded Nursing Care" for further information.

If you would like more information please ask a member of staff for information leaflet- "Supporting you to leave hospital when you may need ongoing care".

## Financial help and advice

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Due to your illness your income may have been affected. If you need financial help or advice the following organisations may be able to advise you.

### **Citizens Advice LeicesterShire Macmillan Helpline**

A free benefits advice service for those affected by cancer in Leicester, Leicestershire and Rutland.

Tel: 0300 456 8400

### **Age UK Leicester Shire and Rutland**

Provides free independent and confidential advice and information to people aged 50 and over.

The Information and Advice helpline can be contacted between 11am to 4pm, Monday to Friday.

Tel: 0116 299 2278

### **Macmillan Cancer Support**

Macmillan Cancer Support national telephone advice service for people with cancer, their families and carers.

Call freephone: 0808 808 00 00



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## **Department for Work and Pensions (DWP)**

The DWP is responsible for social security benefits. Visit [www.gov.uk](http://www.gov.uk) for information and practical advice about public services.

The contacts below may be of use, but if you need to see someone, it may be possible to make you an appointment with a local advisor. Please contact the Cancer Information and Support Centre or your Nurse Specialist for further information.

### **Attendance Allowance helpline**

Telephone: 0800 731 0122

Textphone: 0800 731 0317

### **Personal Independence Payment (PIP) (new claims)**

Telephone: 0800 917 2222

Textphone: 0800 917 7777

### **PIP enquiry line (existing claims)**

Telephone: 0800 121 4433

Textphone: 0800 121 4493

### **Carer's Allowance**

Telephone: 0800 731 0297

Textphone: 0800 731 0317

### **New-style Employment & Support Allowance (new claims)**

Telephone: 0800 328 5644

Textphone: 0800 328 1344



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## **Employment & Support Allowance (existing claims)**

Telephone: 0800 169 0310

Textphone: 0800 169 0314

## **Universal Credit**

Telephone: 0800 328 5644

Textphone: 0800 328 1344

We encourage that people seek benefits advice before contacting the above numbers due to the changes that are taking place in the benefits system.

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## **Help with health costs**

If you receive certain government benefits or have a low income you may be entitled to help with certain health costs, such as travel costs to and from hospital.

There is more information about this later in this booklet. Also, an information booklet (HC11) is available from your GP or hospital, or you can contact the Macmillan Information and Support Centre for more details.

**Tel: 0116 258 6189**

## Free prescriptions

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All people undergoing treatment for cancer, the effects of cancer or the effects of cancer treatment are entitled to free prescriptions. If you have not already got an exemption card please ask your doctor, nurse or therapy radiographer for an exemption application form, or ask at the Macmillan Information and Support Centre.

## Local support groups and charities

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Self-help groups can provide advice and support to people with cancer and those who care for them. These groups often consist of people who have experience of more than one particular type of cancer. They give you the chance to meet and talk with people affected by cancer.

Many self-help groups offer the opportunity to speak to someone on a one-to-one basis, over the phone or in person.

For details of local support groups please contact the Macmillan Information and Support Centre.

**Tel: 0116 258 6189**

### **Sue Young Cancer Support in Leicestershire and Rutland**

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Provides practical and emotional support to anyone affected by a cancer diagnosis (patients, family members and carers).

**Tel: 0116 223 0055**

**Website: [www.sueyoungcancersupport.org.uk](http://www.sueyoungcancersupport.org.uk)**



## **The Leicester, Leicestershire and Rutland Hospice (LOROS)**

LOROS Hospice is a local charity. We deliver free, high quality, compassionate care and support to terminally ill patients, their family and carers.

### **We offer:**

- Specialised care for those over 18 with complex problems who are suffering from a terminal illness when cure is no longer possible. Our care is unique to each individual.
- Short-stay inpatient care for symptom management – with help, half of these patients go home
- End of life care
- Outreach support in the patient's home:
  - Community Nurse Specialist Team
  - Specialist palliative care doctor visits
  - Volunteer Home visiting service
- Counselling and psychological support
- Complementary therapy service
- Medical outpatient clinics at LOROS and in the community
- Lymphoedema clinic
- Palliative day therapy and drop in service
  - Telephone befriending service
- Community Nurse Specialist Advice Line – 8am – 6pm 7 days per week





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## **How to access LOROS services**

- Patients are accepted from across Leicester, Leicestershire and Rutland
- Referrals are generally made by a GP, hospital consultant or hospital palliative care team, or are arranged by a Community Nurse Specialist
- Patients eligible for referral are usually suffering from advanced cancer or other life-limiting conditions such as Motor Neurone Disease (MND), heart failure or respiratory failure

**LOROS Tel:** 0116 231 3771

**Website:** [www.loros.co.uk](http://www.loros.co.uk)

## **CLASP - The Carers' Centre (Leicestershire & Rutland)**

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Offers carers support, advice, information, advocacy and counselling

**Tel:** 0116 251 0999

## **Support for Carers Leicestershire**

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A service designed to support carers throughout the county of Leicestershire.

**Tel:** 01858 468 543

**Website:** [www.supportforcarers.org](http://www.supportforcarers.org)

## **MyChoice**

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A directory for care and support products and services for people living within the Leicester City area.

**Website:** [www.mychoice.leicester.gov.uk](http://www.mychoice.leicester.gov.uk)

## **First Contact Plus - online tool**

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Helps adults in Leicestershire find information about a range of services all in one place.

**Website:** [www.firstcontactplus.org.uk](http://www.firstcontactplus.org.uk)

## National charities and statutory organisations

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There are many national groups that provide support and information to cancer patients and their families. For details of these please contact the Macmillan Information and Support Centre.

**Tel: 0116 258 6189**

### **Macmillan Cancer Support**

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Macmillan Cancer Support gives cancer patients and their families the up-to-date information, practical advice and support they need to reduce the fear and uncertainty of cancer.

Also publishes booklets on different types of cancer and living with cancer.

**Freephone: 0808 808 00 00**

**Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)**

Interpreters are available for non-English speakers.

## Someone to talk to

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Cancer has a major emotional impact on people's lives. It not only affects the patient, but family and friends as well.

Many patients and those close to them believe that they should be able to deal with the situation on their own. Sometimes this may not be the case; talking things over can often help you make some sense of what is happening to you.

Finding the way that works for each individual is not always simple. This is because each patient has different needs and different aspects or consequences of their illness to talk about. A network of many people may be required. Initially, this begins with family and friends, but from time to time you might find it difficult to talk to those closest to you. At this stage, you may feel the need to talk to "other people" with whom you feel comfortable.

It is important to recognise that you may require different help at different times in your illness.

### People who can help

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The doctors looking after you recognise and understand the emotional impact of cancer, but there are many others who can help. We have included below some of the people you may wish to talk to. You might feel that one, or a combination, of these would suit your needs.



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## **Other patients**

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Very often patients find it both reassuring and helpful to talk to other people who are in a similar situation. Sometimes sharing an experience with another patient can lessen the stress and burden of cancer and take away the feeling of isolation.

You may meet other patients when attending for treatment, or you could join a local or national support group. In addition, there are Internet forums where cancer patients can “talk” to each other. For details of support groups and forums please contact the Macmillan Information and Support Centre.

**Tel:                    0116 258 6189**

## **Nurses**

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You are likely to have a lot of contact with nurses throughout your illness, and they are often able to provide emotional support.

## **General Practitioners**

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Your GP will be very much involved in your cancer journey, and will be a source of advice and information for you. He or she may be able to put you in touch with local groups that can provide the assistance you need.

## **Cancer nurse specialists (key workers)**

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These nurses offer emotional support and practical advice to people with cancer and those close to them. They will be involved with you from the point of diagnosis and beyond.



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## Therapy Radiographers

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If you have radiotherapy, you will see the therapy radiographers regularly. They are trained to listen to your concerns and to counsel, help and advise you.

## Counselling Services

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Counselling can provide a private opportunity to talk to someone about anything that concerns or troubles you. Counselling is not the same as advice. It aims to help you to find your own way of responding to your particular circumstances. Your doctor or nurse can put you in touch with a professionally trained counsellor.

Counselling may not always be available on the NHS. However, there are some local organisations that provide free counselling to cancer patients and their families. For details of these please contact the Cancer Information and Support Centre.

**Tel:                    0116 258 6189**

## VitaMinds

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Works in partnership with the NHS in Leicester, Leicestershire and Rutland to offer a range of short-term psychological therapies.

**Tel:                    0330 094 5595**

**Website:            [www.vitahealthgroup.co.uk](http://www.vitahealthgroup.co.uk)**



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## **Sue Young Cancer Support in Leicestershire and Rutland**

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Sue Young Cancer Support aims to support you emotionally. You can self-refer or be referred by your GP or other health care professional. They can offer six counselling sessions.

**Tel: 0116 223 0055**

Your GP may also be able to advise you about the psychological support available locally.

## **Spiritual and Religious Support (Chaplaincy)**

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Upon receiving a diagnosis of cancer many patients face times of great upheaval. This may lead to deep distress or “spiritual pain” as you try to come to terms with your illness. The chaplaincy services across the area provide spiritual, emotional and religious support to patients, visitors and staff of all faiths and outlooks.

Spiritual support is not necessarily “religious”.

It includes listening and talking, helping patients work through the implications of their illness.

Chaplains can also provide religious support where this is requested, such as saying a prayer or offering a religious rite of your faith.

The chaplains and chaplaincy volunteers are drawn from a variety of backgrounds. These include Baha’i, Buddhist, Hindu, Jain, Jewish, Muslim, Sikh and various Christian denominations. There is also a non-religious pastoral carer in the UHL Chaplaincy Team.



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## **Contacts**

### **University Hospitals of Leicester:**

#### **Glenfield Hospital Chaplaincy**

Tel: 0116 258 3413

Email: [chaplaincy@uhl-tr.nhs.uk](mailto:chaplaincy@uhl-tr.nhs.uk)

#### **Leicester General Hospital Chaplaincy**

Tel: 0116 258 4243

Email: [chaplaincy@uhl-tr.nhs.uk](mailto:chaplaincy@uhl-tr.nhs.uk)

#### **Leicester Royal Infirmary Chaplaincy**

Tel: 0116 258 5487

Email: [chaplaincy@uhl-tr.nhs.uk](mailto:chaplaincy@uhl-tr.nhs.uk)

### **Community Hospitals & Mental Health Services:**

Tel: 01509 564218

Email: [lpt.chaplaincy@nhs.net](mailto:lpt.chaplaincy@nhs.net)

### **The Leicester, Leicestershire and Rutland Hospice - LOROS**

Tel: 0116 231 8411

Email: [andrewmartin@loros.co.uk](mailto:andrewmartin@loros.co.uk)

Each Leicester hospital also provides a quiet reflective space for people of all faith and none. These can be used for personal prayer/reflection or just for some peace and quiet. At specific times there are public acts of worship led by one of the faith leaders. Chaplains are also available to visit you on the wards.

## What to do if you are unhappy with your treatment

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If you are concerned or unhappy at any time with your treatment or care, you have the right to say what your concerns are, and to have them dealt with.

**Let people know.** Complaints or concerns are welcomed as they help people who provide the service to know where to improve and what action to take. Sometimes just by talking to the right person you can get things sorted out. You may wish to talk to, or write to, the person in charge of the service about which you have a complaint or concern.

If you would like to make a formal complaint please ask a member of staff for the appropriate leaflet or contact the PILS service (see below).

**Patient Information and Liaison Service (PILS)** is a service for patients, relatives and carers. The aim is to provide a confidential listening and support service, and also information about the hospital, treatment and services provided. If you have any complaints or compliments please contact the PILS service.

**Freephone: 0808 178 8337**

**Advocacy.** You may prefer someone to speak and act on your behalf. They can be a member of your family, a friend or someone from one of the organisations detailed in this booklet. There are also advocacy services available. For further details please contact the Macmillan Information and Support Centre.

**Tel: 0116 258 6189**



# Your health records



## Access to health records

Under the 1998 Data Protection Act, you have the right to access your health records, subject to certain safeguards. If you would like access to your hospital records please contact the Access to Health Records Department.

**Tel: 0300 303 1563 (option 5)**

## Copying letters to patients

You can receive copies of letters written about your illness and care.

If you would like copies of letters, please let your consultant or their secretary know.

## Cancer registration

When a person is diagnosed with cancer in England information about them is automatically collected by the National Cancer Registration and Analysis Service, which is part of Public Health England. This data tells us how many people are diagnosed with cancer, what treatments they are having, what drugs are effective and whether the overall picture is getting better or worse.

This information is vital to help plan cancer services and identify where further progress is needed so that we can improve the lives of all people affected by the disease.

For more information on Cancer Registration in England visit **[www.ndrs.nhs.uk](http://www.ndrs.nhs.uk)** or pick up a cancer registration leaflet in your clinic.

## Transport services

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### Getting to the hospital

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Most people have to get themselves to hospital. Many patients are able to drive themselves to hospital. This is perfectly all right unless your GP or a member of your healthcare team has advised you otherwise.

You will find all the hospitals signposted from the city centre and ring-road. Details of how to get to the individual hospitals will usually be sent to you prior to your admission or attendance. However, if you require a map or directions please contact the Macmillan Information and Support Centre.

**Tel: 0116 258 6189**

### “Hospital Hopper” Bus

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The Hospital Hopper is intended to provide a quick and direct link between the three main hospital sites and is a limited stop service. The service is available from Monday to Friday each week.

For further details of route stops and timetables please contact the Macmillan Information and Support Centre.

**Tel: 0116 258 6189**



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## **Ambulances and ambulance cars**

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Ambulances and ambulance cars can only be provided in cases of special medical need. This may be a serious illness or where the journey cannot be made without special transport. Your own GP will be the best person to judge if you need ambulance transport to take you to the hospital.

TASL Patient Transport Service can be contacted on

**Tel: 0345 241 3012**

## **Car Parking**

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For any enquiries regarding car parking on any of the three UHL sites.

**Tel: 0116 204 7888**



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## **Bus services**

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For information on how to get to all the local hospitals please contact Traveline.

**Tel:** 0871 200 22 33

**Website:** [www.traveline.info](http://www.traveline.info)

## **Trains**

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Leicester train station is located on London Road, Leicester. There is a taxi rank inside the station, or you can catch the Hospital Hopper bus.

For details of train times please contact Traveline.

**Tel:** 0871 200 22 33

**Website:** [www.traveline.info](http://www.traveline.info)

## **Leaving hospital**

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If it is necessary on medical grounds for you to travel by ambulance, hospital car or hospital taxi when you leave the hospital, all arrangements will be made for you by the hospital staff. If you are concerned about this, ask your nurse or the doctor responsible for your treatment.

## **Travel expenses to and from hospital**

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If you have to travel to hospital for treatment, you may be able to claim a refund on your bus or train fares or petrol and parking costs.

You can claim help with travel costs if you or your partner (including civil partner) receive any of the following benefits:

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- Income Support
  - Income-based Jobseeker's Allowance
  - Income-related Employment and Support Allowance
  - Working Tax Credit (WTC) with Child Tax Credit (CTC)
  - WTC with a disability element or a severe disability element
  - CTC but you're not eligible for WTC
  - Pension Credit Guarantee Credit
  - You receive Universal Credit and meet the criteria

**You can also claim for help with travel costs if:**

- you're named on, or entitled to, an NHS tax credit exemption certificate (if you do not have a certificate, you can show your award notice) – you qualify if you get child tax credits, working tax credits with a disability element (or both), and have income for tax credit purposes of £15,276 or less
- you have a low income and are named on certificate HC2 (full help) or HC3 (limited help) – to apply for this certificate, you should complete the HC1 form: claim for help with health costs (PDF, 218kb), which is available from your local hospital, Jobcentre Plus offices or the NHS print contract order line on **0300 123 0849**

Patients who are not in receipt of a qualifying benefit, but are on a low income, and whose savings are less than £16,000 (or £23,500 if in a care home) may be eligible for assistance with their NHS travel expenses.

Please contact the Cancer Information and Support Centre for further information.

**Tel: 0116 258 6189**

## Interpretation and translation services

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There are many different languages spoken by people living in Leicestershire. It is vital when going to hospital that patients and staff are able to understand each other.

If you are coming to hospital as a patient and your first language is not English, or you use sign language, please let the clinic, ward or department know in advance. This will allow us to make arrangements for translation and interpretation services to be provided.

## Dictionary of terms



**Adjuvant therapy:** A treatment given in addition to the main treatment (for example, chemotherapy as well as surgery) to try to prevent a cancer from coming back.

**Alopecia:** Hair loss.

**Benign:** Not cancerous. Favourable for recovery.

**Biopsy:** The removal of a sample of tissue for examination.

**Bone scan:** A bone scan looks for abnormalities in the bones. A bone scan can look at a particular joint or bone. In cancer diagnosis, it is more usual to scan the whole body.

**Bronchoscopy:** An investigation to examine the inside of the lung.

**Cancer:** A growth containing abnormal cells, which invade and destroy surrounding tissues, and can spread to other parts of the body.


**Cannula:** A small tube inserted into a vein to allow fluids to be given. May also be used to take blood samples.

**Carcinoma:** Cancer which arises in the tissue that lines the skin and internal organs of the body.

**Catheter:** A flexible tube used to introduce or remove fluid. For example, urinary catheter.

**C.diff (Clostridium difficile):** A diarrhoea-causing bug.

**CT (Computed Tomography) scan:** Produces a cross-section image of the head and body, which is then analysed by computer.



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**Endoscopy:** A procedure that enables views inside the body through a small tube passed into the digestive system.

**Haematologist:** A doctor who specialises in the treatment of blood disorders.

**Hickman line:** A Hickman line is a fine tube inserted under the skin of your chest into a vein. It can be used for giving drugs, blood and nutrition, or for taking samples.

**Histology:** The microscopic study of body tissues in order to diagnose illness.

**Hormone therapy:** Treatment that alters the level of hormones in the body to treat cancer.


**In situ:** Literally means “in its original place”. Can be used to describe the earliest stage of cancer, when it is limited to its area of origin.

**Lymphatic system:** The system of lymph nodes and the vessels or small tubes that connect them.

**Lymph nodes:** Lymph nodes are located throughout the body, and filter out dangerous substances. They also produce infection-fighting cells called lymphocytes.

**Lymphoedema:** Swelling, usually in the arms or legs, which occurs because the lymph vessels are damaged or blocked., This can occur following some treatments for cancer, or may be due to cancer itself.





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**Malignant:** Cancerous. Malignant tumours can invade and destroy surrounding tissues and have the capacity to spread.

**Metastases:** The spread of cancer from one part of the body to another, by way of the lymphatic system or bloodstream.

**MRI (Magnetic Resonance Imaging) Scan:** Uses radio waves, rather than x-rays, to produce pictures of the body. These can then be analysed by computer.


**MRSA (Methicillin Resistant Staphylococcus Aureus):** A bacterial infection that is resistant to the majority of antibiotics.

**Neoplasm:** See Tumour.

**Palliative care:** Total care of the person, which puts the emphasis on maintaining quality of life, not just on trying to cure the cancer.

**Pathology:** The branch of medicine concerned with the examination of diseased tissues.

**PET (Positron Emission Tomography) scan:** Uses a low-dose radioactive sugar to measure the activity of cells in different parts of the body. Areas of cancer are usually more active than surrounding tissue.



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**PICC line:** A PICC line is a fine tube inserted into a vein in your arm. It runs up the vein inside your arm and ends up in a large vein in your chest. It can be used for giving drugs, or for taking blood samples.

**Primary cancer:** The site of the first growth of abnormal cells that form a cancer.

**Primary care team:** A group of healthcare professionals, such as your GP and district nurse, working in the community, offering treatment and care to patients when in their own homes.

**Prognosis:** An assessment of the expected future course and outcome of a person's illness.

**Sarcoma:** A malignant tumour that arises from bone or muscle, or the connective tissue that joins them.

**Secondary cancer:** See Metastases.

**Stoma:** An artificial opening between an organ and the skin surface, formed by surgery. There are different types, including a tracheostomy (formed from the windpipe), ileostomy (formed from the small bowel), colostomy (formed from the large bowel), and urostomy (formed from the bladder).

**Syringe driver:** A small, portable, machine that administers pain killing and/or other drugs under the skin. It removes the need for frequent injections.

**Terminal illness:** Active and progressive disease that cannot be cured. Curative treatment is not appropriate, but palliative care is.



**Tumour:** An abnormal lump, or mass of cells (neoplasm), that can be either benign or malignant.

**Ultrasound scan:** An imaging technique that uses sound waves to create a picture of the internal organs.

If you hear any terms you do not understand, please ask a member of your healthcare team to explain them to you.

## Your own notes



It is important that you ask any questions you may have. This will help you to fully understand the procedures and treatment you will have.

You may have questions for the doctor, or any other member of your healthcare team, and they should be able to help you understand and enable you to become involved in your treatment.

It may help you to write questions down before your visit to the hospital.

**Names of your team:**

**Consultant:**

[illegible]

[illegible]

[illegible]

[illegible]

## Language support and interpretation

If you need help understanding English, please inform a member of staff or your GP. They will arrange for an interpreter or a linkworker to help you talk about your treatment and wishes.

With thanks to all patients, carers and healthcare professionals who have contributed to this booklet.

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email [equality@uhl-tr.nhs.uk](mailto:equality@uhl-tr.nhs.uk)

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

إذا كنت ترغب في الحصول على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો.