



Radiotherapy to the spine for primary spinal cord tumours

A guide for patients and their carers



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Christie website

For more information about The Christie and our services, please visit **www.christie.nhs.uk** or visit the cancer information centres at Withington, Oldham or Salford.

This booklet tells you about radiotherapy treatment for primary spinal tumours. The Christie is a specialised radiotherapy centre, and patients come for treatments that are not available in general hospitals. If you are having radiotherapy as an inpatient please bring this booklet with you.

It is important that your family and friends feel well-informed and understand what is happening. Please share this booklet with them. Families and carers can have a role in helping you. If you would like more detailed information about your own treatment, please ask a member of staff who is caring for you: your doctor, nurse or radiographer.

You may have heard about radiotherapy from people you know or from the patients at The Christie. Please remember that each patient is an individual and that their information may not apply to you.

What is radiotherapy?

Radiotherapy uses exact, carefully measured doses of radiation to treat diseases. It uses high energy X-rays which destroy the tumour while doing as little harm as possible to normal cells. It is given in small, equal doses over a specified period of days or weeks.



Please note:

Mobile phones can interfere with the treatment equipment. Please look out for signs letting you know if it is safe to use your mobile phone. If you do have one with you, you may need to turn it off.



Specially trained professionals, therapeutic radiographers, operate the treatment machines which direct high energy rays to the precise area needing treatment.

The specific amount of radiation (dose) and number of treatments you will need depend on the exact type of tumour you have. This means that you may find that you are having a different number of treatments from other people you meet here at The Christie.

External beam radiotherapy can be delivered in many different ways using high energy radiation beams. These can either be photons, electrons or protons. Photons and electrons are delivered from a machine called a linear accelerator whilst protons are delivered from a machine called a cyclotron.

The Christie NHS Foundation Trust now provides a proton beam therapy service. However, it is not appropriate to treat all kinds of cancers with proton beam therapy. This will be decided by your oncologist and discussed with you.

If it is appropriate to treat you with protons, there may be occasions when part of your treatment is given with photons. This will be discussed during the consent process.

How does the radiotherapy work?

Our bodies are made up of cells. All cells are able to grow and divide. When radiation hits a cell that is dividing, the cell will be damaged. Normal healthy cells are able to repair this damage, however tumour cells are much less able to repair this damage and so more of the tumour cells will be destroyed.

Agreeing to treatment

Consent to treatment

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had The Christie's written description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you. Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

Radiation can be harmful to an unborn child. It is important to let the radiographers know if you have missed a period, or suspect that you might be pregnant before you have any scans or treatment.

What are the benefits of treatment?

The aim of treatment is to control the tumour. The benefits vary between different people and your doctor will discuss the specific benefits to you.

Are there any alternatives to this treatment?

Treatment for spinal tumours can include surgery, radiotherapy, chemotherapy, other medication or active surveillance (watchful waiting) or a combination of these. Alternatives to radiotherapy may include one or more of these options. Your consultant will discuss this with you.

What will happen if I do not have this treatment?

Without treatment the spinal tumour may grow and cause further symptoms. If you are worried about having treatment or you would like to consider not having treatment, please contact your neuro-oncology specialist nurse, consultant or GP. You can change your mind about having treatment at any time before you start radiotherapy. This will not affect your relationship with the medical staff. If you want to have treatment it is important to complete it, so that the treatment is effective.

Preparation for treatment

The specialist doctor who will look after you is a clinical oncologist. They will ask you some questions, examine you and explain your treatment. A team of doctors including consultants and registrars as well as specialist nurses, radiographers, occupational therapists and physiotherapists will care for you. Once your treatment has been decided, we will give you an appointment for your treatment preparation.

Cast or mask making

Occasionally, people having radiotherapy to the spine have to wear a plastic mould while they are having treatment (see picture). This helps to keep your head and spine still during the treatment and marks can be drawn on the mask or cast to ensure that the treatment is given to the same area each day.



Your mask or cast will be made in a room called the mould room. The mould room staff will discuss the procedure with you. Many people, especially if they are a bit claustrophobic, worry about

having a mask prepared; however, most people cope very well. Help from our complementary therapy (or 'CALM') team is available if you need it to help you relax. You will have the preparation as an outpatient even if you have your treatment as an inpatient.

Permanent marks

Depending on the location of your tumour, the radiographers might need to discuss with you the possibility of having small permanent marks. To help the radiographers ensure you are lying in the correct position every day, with your permission, several little marks will be placed under your skin surface. These marks are very small spots of ink which are approximately the size of a full stop. They are placed under your skin using a small needle and although the marks are permanent, they do fade over time.

Please do not worry about these marks; the radiographers will discuss them with you in more detail when you attend for your planning appointment.

Scans

To help with the planning of your treatment you will have a CT scan. The scans which are undertaken to plan your radiotherapy are solely aimed to give enough information to plan the radiotherapy accurately. These scans are not diagnostic and therefore do not give sufficient information to assess the status of your cancer or any other abnormalities.

If you need a mask, these images will be taken while you are wearing the mask that has been made for you. Some patients also need an MRI scan to help with treatment preparation.



What happens when you have your treatment?

On the day of your first treatment, you will come to the radiotherapy department. If you are an inpatient a porter or clinical support worker may bring you to the department. You will have already visited the department as part of the preparation for treatment and you will have met some of the therapeutic radiographers.



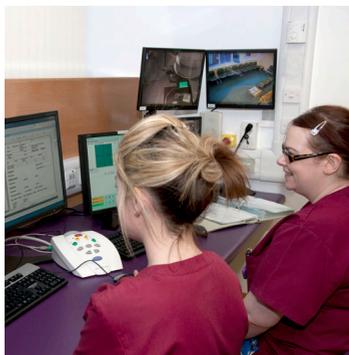
Before the treatment begins a member of staff will explain what will happen during the treatment. If you have any questions or worries please feel free to discuss them with the radiographer. The Christie is a training centre, so you may meet radiography students who may be involved with the delivery of your treatment under close supervision.

Radiographers operate the radiotherapy machines to give you the precise treatment prescribed by the doctor. On each treatment visit they will ask you how you are feeling and ensure that you are coping well as the treatment progresses. The radiographer will help you on to the treatment bed, put your mask on you (if applicable) and adjust the bed and the machine to the exact positions that are needed. They will ask you to remove any clothing or jewellery including earrings that are in the area being treated. During the treatment you need to keep as still as possible.

The radiotherapy machines are quite big and if you have never seen one before you might feel anxious. There is no need to worry – the treatment is absolutely painless. The radiographers are there to support and reassure you. Once your treatment has been set up and the radiographers are happy that everything is all right, they will leave the room

to switch the treatment on. They will be watching you carefully on a closed circuit television system.

The treatment is normally given from a number of different directions (beams) depending on your individual treatment plan. It may only take a minute to actually give each beam but the whole treatment session may take between 15 minutes and 1 hour. Some people worry that they will be enclosed by the machine but this will not happen. The machine can move around you, but nothing will press down on you. The treatment machines make a buzzing noise when they are switched on. This is how you will know when the treatment is happening. If you become worried, anxious or do not feel well while the treatment is being given, just raise your hand and the radiographers will interrupt the treatment and come in to you immediately.



The prescribed radiation dose and the number of days over which it is given vary between patients. Treatment is given Monday to Friday including bank holidays. There is usually no radiotherapy given on Saturdays and Sundays and this is taken into account when your treatment is planned. Treatment days will be changed and may include Saturdays and/or Sundays around the Christmas and New Year period.

You will usually be treated on the same machine throughout the course of your radiotherapy. However, the machines need to be serviced frequently and as a result you may be treated on a different machine. The radiographers treating you will let you know about this. You will not miss any treatment because of this and the treatment will be exactly the same.

It is very important that you do not miss treatment days as this may make your treatment less effective. If you feel you are unable to attend for any reason please telephone the staff on your treatment machine and discuss the problem with a radiographer. Call the radiotherapy department on **0161 446 3485**.

We will give you the date and time of your first treatment visit when you attend for your planning visit. Treatment usually starts within a few weeks of your planning visit.

Some questions about radiotherapy

Will it hurt?

No. You will feel no pain at all while you are actually having the treatment.

Is it safe?

Radiation used in medical treatment is given in controlled, carefully measured doses. The aim is to treat the illness whilst minimising the dose to the normal tissues.

Will I be radioactive?

No. Patients treated by X-rays do not become radioactive. The radiation does not stay in your body after treatment, so you cannot do anyone else any harm. It is safe for you to mix with other people and to have visitors if you are on the wards.

I already have problems with my general health. Will radiotherapy treatment make them worse?

Not usually, but the treatment may make you feel more tired than normal. Please tell your treating team about any existing medical conditions and continue with any medication that you may be taking. Please ask your Christie doctor if you are worried about any other health problems.

When will I see the doctor?

While you are having radiotherapy, you will see a member of the team every week. This may be the consultant, registrar, specialist radiographer or nurse. The purpose of this visit is to make sure that you are progressing well through treatment as expected, and to deal with any side effects that you may be having. Please tell the team member you see if you are having problems so that you can get help with any side effects. If you feel you need to see the doctor at any other time please speak to a radiographer who will help you.

Can I come for treatment at any time of the day?

If you are having treatment as an outpatient, the radiographers will give you an appointment time for the first treatment when you attend for your planning session. After that you can arrange with your treating team a time that suits both you and the machine. Please try and be as flexible as possible. The time you prefer may not be available at the start of your treatment because of the large patient numbers on the unit.

If you need a specific time, please give the treating team as much notice as possible, although the department cannot guarantee to meet all requests. The time we give you may vary half an hour either way each day due to emergencies. Please check your appointment time for the following day before you leave in case of any changes. We will give you a morning or afternoon appointment to fit in with your consultant's clinic.

If you are an inpatient, the treating team will call for you when they have a free slot. If you are going home for the weekend, please let the staff know and they will do their best to treat you as early as possible.

Will I be treated as an outpatient or an inpatient?

You will usually have your treatment as an outpatient. Some people continue to work during part of their treatment. However, after daily travel and treatment, you may feel tired and need to rest.

Your doctor will have discussed with you about travelling daily for your treatment as an outpatient. However, if you do become unwell during your treatment we may admit you as an inpatient to support you through your radiotherapy. You will not have to stay in bed, so bring suitable day wear such as tops and skirts or trousers. Treatment usually takes up only a small part of the day and, if you are well enough, you may be able to go out – check with the ward staff first.

What happens if I need transport to and from The Christie?

Many patients are able to ask a friend or relative to help them with travelling for their treatment. However if you think you will need ambulance transport please discuss this with a radiotherapy support worker or radiographer on your first visit to the radiotherapy department.

Ambulance transport can be arranged subject to eligibility criteria based on medical need. There also needs to be a medical need for you to bring an escort on hospital transport. Ambulance transport will be arranged as a block booking for all of your treatments. There can be delays for some time either side of your appointment because of the high demand for transport. Please take this into account when you are deciding whether to use ambulance transport or not.

Hospital transport is provided by several different ambulance services. Contact the transport liaison office at The Christie directly on **0161 446 8114** or **8143** for advice and bookings (Monday to Friday, 8.00am – 6.00pm). Patients attending The Christie at Salford should ring **0161 918 7800** to

arrange all their transport.

Side effects of treatment

Side effects can be mild or more troublesome depending on the strength of the radiotherapy dose and the length of your treatment. Radiotherapy can cause general side effects such as tiredness, but there are some effects which are specific to having radiotherapy to the spine. While you are having radiotherapy it is very important that you continue to take the medication prescribed by your doctor. Do not change anything unless you have discussed this with your doctor first.

Feeling sick

Occasionally some people may have feelings of sickness. This can usually be effectively treated by anti-sickness drugs which your treating team can prescribe.

Change in appetite

You may find that food tastes different or you have a metallic taste in your mouth. If your appetite is affected, try to eat little and often. If you don't feel like eating, you can replace meals with nutritious, high-calorie drinks. These are available from most chemists and can be prescribed by your GP.

Sore throat

Depending on the location of the tumour, some people may develop a sore throat, discomfort on swallowing or a dry cough. All of these can usually be treated with medication which your treating team can prescribe.

Bladder or bowel disturbance

Depending on the location of the tumour, some people may develop a loosening of their bowels which may develop into diarrhoea. Some may also find that they have to pass urine more frequently. If you notice any changes in your bowel or bladder functions please tell a member of your treating team. These can be effectively managed with medications which they can prescribe.

Tiredness

Radiotherapy often makes people feel tired. It builds up towards the end of treatment and can last for several weeks after the treatment has finished. Take rests when you need to but try to maintain your normal daily activities as much as you can be because we know that this can be beneficial. The Macmillan leaflet 'Coping with fatigue' provides further advice on this and is available from the cancer information centres.

Recurrence or worsening tumour-related symptoms

Some people find the symptoms of the spine tumour recur or temporarily get worse either during the course of radiotherapy or after the treatment has finished. This can make them think that their tumour is getting worse but, in fact, it is a reaction to the radiotherapy treatment. If you find this happening to you, it is important to discuss it with the doctor, nurse or radiographer, who will be able to give you the right advice, treatment and medical support.

Skin changes

Some people develop a skin reaction, similar to sunburn, while having radiotherapy. This normally happens about half way through the treatment (usually after 3 - 4 weeks). People with pale skin may find that the skin in the treatment area becomes red and sore and itchy. People with darker

skin may find that their skin becomes darker and can have a blue or black tinge. The amount of the reaction depends on the area being treated and the individual person's skin. Some people have no skin problems at all.

You can continue to use your normal daily moisturiser to help with this. You do not need to change from this unless you find that it starts to irritate your skin during your treatment. We do not recommend that you use any moisturisers that are perfumed or contain metal agents as they may increase any skin reaction you have.

Your radiographers will be looking for skin reactions, but you should let them know as soon as you feel any soreness. Ask the nursing or radiotherapy staff for a copy of 'Skin care during and after your radiotherapy treatment' which has information about coping with problems such as skin changes.

Infertility

Depending upon the location of the tumour, this treatment can cause infertility which is permanent. If fertility is an issue for you, please discuss this with your doctor. If appropriate, it is possible to arrange for you to see a fertility specialist.

Late or permanent side effects

It is possible for some types of reaction to occur months or years after the treatment has finished. These late effects will depend on the part of the spine being treated and your doctor will discuss any possible late effects with you before you start the radiotherapy treatment.

Cranio-spinal radiotherapy

A small proportion of people with rare types of tumours will need treatment to their whole brain and spine. This

is known as cranio-spinal radiotherapy. In addition to the side effects outlined above, this treatment can cause bone marrow suppression (drop in blood levels, in particular, platelets, red cells and white cells), infertility, hormone under-activity (thyroid and pituitary) and loss of hair on the head. The side effects of radiotherapy to the brain are described in the booklet 'Radiotherapy for brain tumours' and will be fully discussed with you by your consultant.

Chemotherapy

Your doctor may recommend some chemotherapy as well as radiotherapy. Chemotherapy is the use of drugs to treat cancer. It can be given as tablets or capsules. Sometimes it can be delivered directly into the bloodstream via a 'drip' or injection. You may have chemotherapy before, during and/or after radiotherapy. If your doctor feels you might benefit from this treatment, he or she will discuss this with you. The staff will give you a leaflet with specific information about the type of chemotherapy that you are going to have.

After the treatment: follow-up and scans

Your side effects may last for some weeks after the treatment finishes so it is important to continue with your skincare routine and take all medicines as prescribed by the doctor.

Your first follow-up appointment will usually be 6 weeks after your last treatment. This will normally be in the outpatient department at The Christie. The doctor will discuss how you have been since your treatment and will often arrange for you to have a follow up scan.

Most patients will have their first follow-up scan carried out 2 - 3 months after the end of radiotherapy treatment. Radiotherapy works slowly and it can take up to 3 months

for treatment effects to settle down and any benefit to be seen. You will then have regular follow-up visits to the clinic with repeat scans arranged once or twice a year or depending on your symptoms.

Some patients ask about 'warning signs' they should look for once the treatment has been completed. There can be different signs depending on where the original problem was. For this reason, you should ask the doctor to discuss this with you. Of course, if you are worried about anything you feel may be related to the tumour or the treatment, please contact us and, if necessary, we can arrange an earlier outpatient appointment for you.

Appointments

Once you are having treatment, if you have a problem with your appointment time, please speak to your treating team as soon as possible. Contact The Christie at Withington on **0161 446 3485** or The Christie at Salford on **0161 918 7800**. It is helpful if you can quote your hospital number – it will be on your appointment card or letter.

If you change your address please let your consultant's secretary know your new address and the details of your new GP.

Driving

All drivers who have a spinal tumour are **legally required to inform the DVLA** of their diagnosis. Patients with a low grade (WHO Grade 1) are normally allowed to drive on recovery. Patients with a medulloblastoma or low grade ependymoma are not permitted to drive a car for a minimum of 1 year. Patients with high grade tumours are not permitted to drive for a minimum of 2 years from the time of their main initial treatment (surgery or radiotherapy).

The DVLA can be contacted at: Drivers' Medical Enquiries, DVLA, Swansea SA99 1TU.

You can also notify the DVLA of your medical condition by phone: **0300 790 6806** (Monday to Friday, 8.00am – 5.30pm; Saturday, 8.00am – 1.00pm).

Full details and advice are also available on the website at: www.dvla.gov.uk

Prescriptions

NHS patients treated for cancer are entitled to free prescriptions. You will need an exemption certificate. They are available from The Christie Pharmacy and from your GP.

Travel and holidays

It is preferred for you not to go on holiday during treatment because we know that the treatment works better if there are no breaks. Most people do not feel like travelling for the first few weeks after their treatment. However everyone is different. It may take 4 - 6 weeks before your side effects settle and it may be some time after this before you feel like going on holiday.

Once you feel like going away, there is no problem travelling within the UK. If you are thinking of going abroad, make sure you have adequate health insurance which includes the diagnosis of your tumour or cancer. This might mean that the cost of your insurance policy is higher than it has been previously. Some people have found it useful to get a quote for their insurance before booking a holiday as this may affect your choice of destination. Even if you are travelling within Europe you should have health insurance as well as the (free) European Health Insurance Card.

More information about this and other things to consider are available in the booklets 'Getting Travel Insurance' and 'Travel and Cancer' Macmillan Cancer Support, which are available from the cancer information centre.

Research at The Christie

The Christie is an international leader in cancer research and therefore you may be approached to take part in a research study or clinical trial. All information will remain entirely confidential and you will always be approached directly to take part in a clinical trial. We will give you detailed written information regarding the trial and its purposes. You will have time to consider your answer, discuss with family and friends and ask questions before you decide whether or not to take part. You are under no obligation to take part in any trials and you cannot be entered onto a trial without giving your consent. If you take part in a clinical trial you will meet the research nurse or research radiographer who help to run the trials. You are free to withdraw from a trial at any time and for any reason. This will not affect any future treatment or care.

Car parking

For parking at the main Withington site, please check the website (www.christie.nhs.uk) for the latest details, or ask at the information centre for a copy of the leaflet 'Travelling and car parking for patients and patient's visitors to The Christie'. The Christie at Salford has designated areas for patient parking with code entry for radiotherapy patients.

Further information

Macmillan Cancer Support

This is a national cancer information charity which runs a cancer information service. The cancer support service free-phone number is **0808 808 00 00** (Monday to Friday, 9am - 8pm). If you are hard of hearing, use the text phone **0808 808 0121**. If you are a non-English speaker, interpreters are available. Specially trained cancer nurses can give you information on all aspects of cancer and its treatment. Information and advice about finance and benefits is also available.

Macmillan Cancer Support publishes booklets which are free to patients, their families and carers. You can get a copy by ringing the freephone number. The information is on their website: www.macmillan.org.uk

There is a booklet called 'Spinal cord tumours' and other information is available on cancer treatments – such as 'Understanding radiotherapy' and 'Understanding chemotherapy'. There are also booklets on living with cancer – some of these are listed below:

- Talking about your cancer
- Lost for words
- Talking to children and teenagers when an adult has cancer
- Cancer and complementary therapies
- Travel and cancer

The cancer information centres have the full range of Macmillan booklets free to patients and their relatives or carers. There are information centres at The Christie at Withington, Salford and Oldham.

Cancer information in your language

If English is not your first language, you can speak to a nurse at Cancer Research UK through a qualified interpreter. The service is free and over 170 languages are available on **0808 800 4040**. You can also view all patient information on The Christie website in many languages using the BrowseAloud function.

BASIC (Brain and Spinal Injury Charity)

Basic provides a specialist resource at the Neurocare Centre in Salford for people with brain related conditions.

BASIC helpline **0870 7500000**
www.basiccharity.org.uk

Christie information

The Christie produces a range of patient information booklets. Some of these are listed below. Booklets are free to patients coming to The Christie and are available from the cancer information centre. If you are an inpatient and would like a copy please ask the ward staff. If you are an outpatient please ask your nurse, doctor or radiographer.

- **Where to get help: services for people with cancer**
This discusses sources of help when you have cancer, where to go for financial help, palliative care and cancer support groups.
- **Eating – help yourself**
This gives advice on eating problems when you don't feel well and you are having treatment. Also see The Christie booklets 'Nutritional products' and 'Eating a regular, easy to chew diet'.
- **Be Active, Stay Active: a guide for exercising during and after treatment for cancer**

A booklet with a simple exercise programme you can follow. There is also more information about coping with fatigue and the benefits of exercise. A short film can be viewed on the website with English subtitles.

Benefits and finance

You may have had to stop work and had a reduction in your income. You may be able to get benefits or other financial help. Personal Independence Payment (PIP) is a social security benefit and has replaced Disability Living Allowance (DLA) for new claimants. It's for people who need help either because of their disability or their illness. You can apply if you are aged 16 – 64.

People aged 65 or over who need help with personal care or supervision could be entitled to Attendance Allowance.

Your carer could get Carer's Allowance if you have substantial caring needs.

Find out more:

- To get a claim pack for Attendance Allowance, call **0345 605 6055** and for PIP call **0800 917 2222**.
- Carer's Allowance: call **0345 608 4321**.
- For benefits advice, contact Maggie's centre on **0161 641 4848** or email **manchester@maggiescentres.org**
The Christie at Oldham has a benefits advice session on Thursday afternoons, call **0161 918 7745**.
- Contact your local social services department for help with equipment and adaptations, or for an assessment of care needs. Visit **www.gov.uk** for further information.
- Macmillan Cancer Support can give advice on helping with the cost of cancer on **0808 808 00 00** or **www.macmillan.org.uk**

Student training

The Christie is a training centre for postgraduate and undergraduate trainees so you may meet students in all areas of the hospital. We train doctors, nurses, radiographers and other therapists in the treatment and care of cancer patients.

Placements at The Christie are an important part of student training, so by allowing them to assist in your care, you will be making a valuable contribution to student education. Students are always supervised by fully qualified staff. However, you have the right to decide if students can take part in your care. If you prefer them not to, please tell the doctor, nurse, radiographer or other therapist in charge as soon as possible. You have a right to do this and your treatment will not be affected in any way.

We also try to respect the concerns of patients in relation to the gender of their doctor and other health professionals.

Useful contacts

Specialist radiographer

0161 446 7197

You can contact our specialist radiographer for queries before, during or immediately after you have completed radiotherapy.

Neuro-specialist nurses

The Christie at Withington

0161 446 8441

Salford Royal

0161 206 0613 or 2073

Contact the neuro-specialist nurses for general advice and support.

Specialist allied health professionals

0161 918 7400

Contact the specialist allied health professionals for queries relating to rehabilitation, mobility, speech and activities of daily living.

For queries about radiotherapy appointments

The Christie – **0161 446 3485**

The Christie at Salford – **0161 918 7800**

Mould room – **0161 446 3525**

For urgent medical queries out-of-hours

The Christie Hotline – **0161 446 3658**

Contacts via your consultant's secretary

Dr H Gattamaneni – **0161 446 3362**

Dr C McBain – **0161 918 7008**

Dr G Whitfield – **0161 918 7197**

Dr Colaco – **0161 918 7197**

Dr S Kennedy – **0161 918 7197**

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard.

If you would like to have details about the sources used please contact patient.information@christie.nhs.uk

Contact The Christie Hotline for
urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**

The Christie at Oldham **0161 918 7745**

The Christie at Salford **0161 918 7804**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check
before making a special journey.

The Christie NHS Foundation Trust

Wilmslow Road
Manchester M20 4BX

0161 446 3000

www.christie.nhs.uk



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