

The Long Term Follow Up Clinic

Information for patients



Introduction

The Long Term Follow Up clinic is for people who;

- Have had cancer or any other condition treated by a cancer specialist (oncologist) during childhood or as a young adult.
- Have had a non-cancerous illness which required a bone marrow transplant during childhood or as a young adult and,
- have completed their treatment.

Why should I attend the clinic?

Support and Education

At your clinic visit you will be given the chance to ask any questions. We will be able to tell you more about the illness and the treatment you had. You will be offered a summary sheet of your treatment. You will also be given the details of your Key Worker. A Key Worker is a person who is a point of contact for you and your family and is able to co-ordinate your care.

Knowing that you have had cancer can be difficult for you, and your family to understand and deal with. If you wish, we can refer you to our psychologist or social work team. They are happy to help you with these types of issues.

Management of Late Effects

Some of the treatment you received may put you at risk of having other problems. These are known as 'late effects'. Late effects may cause problems many years after your treatment. At the clinic we will discuss the possible late effects of the treatment that you had.

It is important that you tell us about any problems you have so that we can check if there are any links with your previous cancer or its treatments. Some late effects may mean that we need to refer you to other specialist doctors.

Monitoring for Late Effects

The late effect that you may be at risk of will depend on the cancer, and the treatment that you had. It is unlikely you will be at risk of all possible late effects.

Here are some examples of late effects:

- There may be a chance that your hormones have been affected. We will monitor this and refer you to a specialist if there are any concerns.
- Some treatments can affect your heart. If you had any of these treatments we will offer you heart scans to check for problems and provide advice about maintaining a healthy heart.
- In some patients the ability to have a child (fertility) may have been affected. If this worries you we will discuss it and, if appropriate, refer you to specialist who can assess and support you further.

You will receive a 'Care Plan' which tells you about any late effects you are at risk of and the recommended tests you should have.

Health Promotion

We can offer you information and advice to help you lead a healthier lifestyle. This could be relating to smoking, alcohol, recreational drugs, sexual health issues or healthy eating and exercise. We can also advise about breast and testicular self-examination.

What will happen at the clinic?

- Your visit may take up to two hours.
- At each visit you will be seen by a doctor, a specialist nurse, or both.
- We may record your height, weight, blood pressure and body mass index.
- You will be asked to fill in a form that asks about any concerns or problems you may have. This is called a Holistic Needs Assessment Form. We will also ask if you are taking any medications and what they are. This form will help the doctor or nurse focus on what is worrying you. We will be happy to discuss healthy lifestyle options with you.
- The doctor or specialist nurse will discuss your previous illness and treatment. They will also give you information about any possible late effects that you may be at risk of and discuss any tests that may be recommended.
- The doctor may examine you.
- We may wish to do some tests, such as blood tests or scans.
- We will discuss your long term follow-up care plan with you

How often will I need to attend?

This will depend on you, the cancer you had, the treatment that you received as well as how you are feeling.

Some patients will need to attend the clinic every year. This may be the medical clinic where you will be seen by a doctor or, the nurse clinic where you will be seen by a specialist nurse.

Some patients will be seen in clinic and then go onto having telephone consultations which may occur every year, then become less frequent.

Some patients will have a combination of clinic visits and telephone consultations.

Who can I contact between my visits?

If you have any questions or concerns between your clinic visits, please feel free to contact your Specialist Nurse Key Worker who can provide you with information, support and guidance about your previous illness and treatment.

If you do not know who your Specialist Nurse Key Worker is, please call the long-term follow-up office on 0113 208 8817 or 0113 2067806.

Who are the Long Term Follow Up Team?

Doctors - We have a team of doctors who are experienced in looking after people who have had cancer and will be aware of any potential late effects you may be at risk of.

Specialist Nurses - they are available in clinic to offer support, information and advice. They are also available at other times if you wish to discuss any concerns or questions you have. Your Key Worker is likely to be a Specialist Nurse.

Social Worker - They are available to offer support and give advice and assistance about issues relating to your previous cancer diagnosis.

Patient Co-ordinator - available to help with your appointments and any queries.

When are the clinics held?

The medical clinic is usually held on Wednesday afternoon in Bexley Wing at St James's University Hospital. You will find the clinic on Level 1, Clinic Suite 1.

There is a nurse-led clinic held each Thursday afternoon in Bexley Wing at St James 's University Hospital. This is on Level 1, Clinic Suite 1.

We also run a telephone clinic for some patients. This is usually takes place between 11.00 and 3.30 each Tuesday.

If you have any questions or concerns at any time, please contact one of the Nurse Specialists in Long Term Follow Up:

Over 18 years age group tel: **0113 206 8769** or **0113 206 8959**

For queries about appointments, please contact the Long Term Follow-up Administration Team on:

0113 206 7806 or **0113 206 8817.**



Leeds Cancer Support

Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of support, in a welcoming environment for you, your family and friends.

We can be found in the information lounges in Bexley Wing and also in the purpose built Sir Robert Ogden Macmillan Centre.

The Sir Robert Ogden Macmillan Centre

The Centre is on the St James's Hospital site and offers a variety of support services including complementary and supportive therapies. These therapies include Reiki, relaxation and visualisation, hand and foot massage and many others. We also offer a weekly exercise class and a monthly support group. You can just drop in for a coffee and a chat anytime.

Contact numbers for Leeds Cancer Support:

Information Centre Level 1 Outpatients Department

Open from 9am - 4pm. Tel: **(0113) 206 8816**

Information Lounge Level -2 Radiotherapy Department

Open from 8.00 - 6.00pm Tel: **(0113) 206 7603**

The Sir Robert Ogden Macmillan Centre

Open from 9am - 4pm. Tel: **(0113) 206 6498**

The above services can be emailed on:

leedsth-tr.Cancersupport@nhs.net.

Maggie's Centre

If you or someone you love has cancer you may have lots of questions. Maggie's is a warm, welcoming place where you can meet people who are experiencing similar things to you. You may also be able to find support groups specific to your needs and get advice and information from their professional staff. You don't need an appointment and all support is free. Open Monday to Friday 9.00 am - 5.00pm. Tel: **(0113) 427 8364**

Address: St James's Hospital (next to the multi storey car park), Alma Street, Leeds LS9 7BE

Email: leeds@maggiescentres.org

Website: maggiescentres.org

Chaplaincy Service

Chaplains are non-judgmental, sympathetic listeners to anyone of any faith, as well as those without a religious faith. They can offer comfort and encouragement. You may ask faith related questions, but that is optional, and it is entirely up to you. They are purely there to give you support. If you wish to contact a chaplain at St James's University Hospital please call:

0113 206 5935 or call the chaplaincy secretary on: **0113 206 4365**

What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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