

Leiomyosarcoma of the Skin

What is this booklet about?

This booklet is designed to give you information about leiomyosarcoma and how it may be treated. We hope it will answer some of the questions that you or those who care for you may have. It is not meant to replace the discussion between you and your doctor but helps you to understand more about what is discussed.

If you have been diagnosed at your local hospital, your care will be transferred to the Queen Elizabeth Hospital Birmingham as it is a specialist centre that has knowledge and expertise in treating and managing leiomyosarcoma and other rare skin cancers.

If you have further questions, please contact your Clinical Nurse Specialist (CNS).

You should have been given the details of your CNS but if you have not, please ask your doctor's secretary to provide them.

What is Leiomyosarcoma?

Leiomyosarcoma is a rare form of skin cancer associated with the muscles of the hair, the muscle surrounding sweat glands or the muscles surrounding the blood vessels and nerves in the skin. They usually occur in those between 40 and 60 years of age and they are more commonly found in men. They usually appear on the extremities, particularly on the hair-bearing skin.

What does Leiomyosarcoma look like?

Leiomyasarcomas usually appear as a single ill-defined swelling which is smaller than 2cm. The overlying skin may be discoloured and appear pink, purple, brown or red. There may be some crusting or ulceration. The swelling may be painful or have an itching or burning sensation and sometimes the swellings may bleed.

How is it diagnosed?

Your diagnosis will have been confirmed by taking a biopsy of the lesion.

The doctor may also examine the rest of your skin, your lymph nodes and will take note of any past illnesses and current medications.

You may be offered a CT scan as this is a rare form of skin cancer and it is helpful to have a baseline scan for comparison should we need it in the future. It is unlikely that we will find anything of concern on this scan however if we do then we may need to complete further investigations. You may be given written information explaining what a CT scan involves.

What is the treatment?

Leiomyosarcomas are treated surgically with a wide local excision. This involves removing the cancer cells and some healthy tissue around them. A process called Moh's micrographic surgery (also known as Moh's) is used. As each layer of tissue is removed, it is examined under a microscope until all cancerous tissue has been removed. Each layer will be taken a few days apart so it may take a couple of weeks for all of the cancer to be removed. This process provides

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the most accurate method of ensuring all cancer cells have been removed and reducing the chances of the cancer returning. You will be given a separate information sheet about this type of surgery.

Your doctor will discuss any alternative treatment options with you.

What happens after treatment?

You will be asked to attend follow-up appointments within the Dermatology Department every 6 months for 3 years after your surgery, however it is important to know that most people treated with Moh's surgery will have no further problems. This appointment will usually be at the Queen Elizabeth Hospital Birmingham.

The role of your CNS

Your CNS (sometimes called key worker) is an experienced skin oncology nurse who works with the other members of the team to provide specialist medical and psychological care to people with leiomyosarcoma and their families.

The role of your CNS is to coordinate any investigations, treatment and follow-up care during your cancer journey. They are there to clarify any information, discuss matters that are important to you, provide emotional support and refer to other professionals if required. It is very important that you are able to have your questions answered and concerns discussed; your CNS will make every effort to ensure this.

You will be given a contact telephone number for the CNS so that you are able to contact them should you have any worries or need further information when at home. If you have not been given this please ask your consultant or contact their secretary for the details.

It may help to write down questions as you think of them so that you have them ready. It may also help to bring someone with you when you attend your outpatient appointments.

Local sources of further information:

Further information

Further information on health and cancer related topics may be found at The Patrick Room:

The Patrick Room

Cancer Centre Heritage Building Queen Elizabeth Hospital Birmingham Birmingham B15 2TH

Tel: 0121 371 3539/3537

About this information

This guide is provided for general information only and is not a substitute for professional medical advice. Every effort is taken to ensure that this information is accurate and consistent with current knowledge and practice at the time of publication. We are constantly striving to improve the quality of our information.

If you have a suggestion about how this information can be improved, please contact us via our website.

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| Please use the space below to write down any questions you may have and bring this with you to your next appointment. |
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Dermatology

Queen Elizabeth Hospital Birmingham Mindelsohn Way, Edgbaston Birmingham, B15 2GW Telephone: 0121 627 2000

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email patientexperience@uhb.nhs.uk.

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