



Merkel Cell Carcinoma

What is this booklet about?

This booklet is designed to give you information about Merkel cell carcinoma 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, you will be sent to a specialist centre that has knowledge and expertise in treating and managing Merkel cell carcinoma. Queen Elizabeth Hospital Birmingham is a specialist centre.

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 Merkel cell carcinoma?

Merkel cell carcinoma is a very rare disease in which cancer cells form a lump in the skin. Merkel cell carcinoma is a cancer that usually occurs in older people, and those who have a weakened immune system. It often occurs on skin that has been damaged by sun exposure. However, it may occur on the trunk, extremities and in other areas of the body. It is more common in men than women, and in those over 50. It is also more common in people with paler skin and in patients with a weakened immune system (for example patients with a transplant or those taking immunosuppressive medication). Merkel cell carcinoma tends to grow quickly and can spread at an early stage so it is important to recognise it and treat it early.

What does Merkel cell carcinoma look like?

Merkel cell carcinoma usually appears as a single painless lump on skin that is exposed to the sun. Merkel cell carcinomas are usually firm and dome-shaped or raised red or violet in colour and they often grow rapidly, over just a few weeks or months.

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 asked to attend a CT scan; as this is a rare form of skin cancer it is helpful to have a baseline scan for comparison should we need it in the future. If we see anything of concern or uncertainty we may need to do further investigations. You will be given written information explaining what a CT scan involves.

What is the treatment?

Merkel cell carcinomas can be treated either with surgery or radiotherapy.

Surgery

Surgery may be used to remove the cancer cells and some healthy tissue around it. You may be given a separate leaflet explaining more about the type of surgery which would be suitable for you.

Radiotherapy

Radiotherapy may be used as an alternative to surgery. The aim is to destroy all of the cancer cells and it will usually treat the same size area that would have been removed with surgery. Radiotherapy is sometimes used as well as surgery if there are particular features of your Merkel cell carcinoma that make us concerned that it has a high risk of recurring.

You may be offered a clinical trial if you are eligible for one that is available at the time of your treatment. If this is the case, the details of the trial will be discussed with you so you can decide if you wish to take part.

Your doctor will discuss any alternative treatment options with you.

What happens after treatment?

You will be asked to attend follow-up appointments with a dermatologist or an oncologist every three months for five years after your treatment. At these appointments, your skin and lymph nodes will be examined for any signs of spread. If Merkel cell carcinoma spreads it usually spreads first to nearby lymph nodes and then may spread to distant parts of the body. You will also be shown how to examine your own skin and lymph nodes in between follow-up appointments. If you are concerned that your cancer has spread between appointments then you should contact the CNS team to arrange an earlier appointment.

What happens if my cancer spreads?

If your cancer spreads, what happens next will depend on where it has spread to and how much disease there is. We will ask you to come in for a CT scan to establish the extent of the spread. Surgery and radiotherapy may still be an option or you may be offered chemotherapy or immunotherapy.

Your doctors will discuss these options in detail and you will be given further written information as appropriate.

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 Merkel cell carcinoma 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 you to other professionals if required. It is very important that you are able to have your questions answered and concerns discussed, and 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.

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.

Information for Patients

Local sources of further information:

You can visit any of the health/cancer information centres listed below:

University Hospitals Birmingham
NHS Foundation Trust
The Patrick Room, Cancer Centre,
Heritage Building, Queen Elizabeth Hospital,
Birmingham B15 2TH
Telephone: **0121 371 3539 / 3537**

Heart of England NHS Foundation Trust
Health Information Centre,
Heartlands Hospital, Bordesley Green,
Birmingham B9 5SS Telephone: **0121 424 2280**

Patient Information Centre
Good Hope Hospital, Rectory Road,
Sutton Coldfield B75 7RR
Telephone: **0121 424 9946**

Sandwell and West Birmingham
Hospitals NHS Trust
The Courtyard Centre, Sandwell
General Hospital (Main Reception),
Lyndon, West Bromwich B71 4HJ
Telephone: **0121 507 3792**

Walsall PACT (Patient Advisory Cancer Team)
Telephone: **0800 783 9050**

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.

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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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 interpreting.service@uhb.nhs.uk.