



MARSU (Midlands Abdominal and Retroperitoneal Sarcoma Unit) Specialist Team

Information for patients newly referred to MARSU and potentially undergoing further investigations

Macmillan Sarcoma Nursing Service

The Macmillan Sarcoma Cancer Nursing Team are based at University Hospitals Birmingham NHS Foundation Trust, to improve the quality of life for those affected by cancer or rare benign conditions.

The aim of the service is to provide help, information and support to any patient with or a suspected sarcoma cancer, as well as patients with rare benign conditions, within the Trust at any stage of their illness.

Reason for referral may be for:

- Emotional support
- Information about cancer and treatment
- Discharge planning with the multi-professional team
- Communicating between patients and other hospitals
- Continuation of care within the community

Macmillan sarcoma clinical nurse specialists (Key worker)

Natalie Harvey
Ruth Buckingham
Sarah Evans
Sarah Webb

Fay Prince
Bernadette Fairley
Gloria Tilt

Shital Supe- Cancer support worker
Tomikee Oyetunde- Business co-ordinator

We can see patients:

- In outpatient clinics
- In nurses clinic
- On the wards

We provide a service between the hours of 08:00–16:00 Monday to Friday (excluding Bank Holidays).

Information for Patients

Our contact telephone details are:

0121 371 6648 (always an answer machine) for symptom related enquires

Email address: sarcomacns.uhb@nhs.net for general enquiries

Name and hospital numbers are required please.

Our address is:

Room 59, 4th Floor (East block)

Queen Elizabeth Hospital

Heritage Building

Mindelsohn Way

Birmingham B15 2TH

Other members of the sarcoma specialist team

Surgeons

Mr A. Desai Secretary Jacqui Littlehales

Mr S.Ford Secretary Helen Hill

Mr M. Almond Secretary Rachel Lappin

Mr F. Tirotta Secretary Jacqui Littlehales

Oncologists

Dr D. Peake

Dr J. Sherriff

Dr M. Jafri

Dr M. Roji

Secretaries Georgina Murphy & Helen Grainger

Histopathologists

Dr P. Taniere

Dr P. Balogh

Radiologists

Dr G. Burkill Dr R. Briard

Dr R. Amir Dr T. Diacon

All the members of the multidisciplinary team meet on a Wednesday morning to discuss each case, to look at results and to plan patients' treatment and care.

Staging investigations

At the hospital

You have seen the sarcoma specialist and you have been asked about your medical history and symptoms. The specialist may have also examined you by feeling the area that is painful or swollen. You may also have been asked to have blood tests to check your general health.

We will have discussed any further tests we may need to help in your treatment during this consultation. Any tests required will be arranged in the outpatient department.

Once you have had the additional tests we will need to discuss the results in our multidisciplinary team meeting on a Wednesday morning. We hope this does not delay things but sometimes we may need

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additional time to discuss things further with our specialist colleagues. The CNS team will not give diagnostic results over the phone.

MRI scan

If the sarcoma specialist has told you that you need an MRI scan, we endeavour to complete this within two weeks however if your case is especially complicated this may take longer as there are only a few specialist radiologists who are able to accurately report these scans for the sarcoma unit. An MRI uses magnetic fields to build up a picture of body tissues and structures. Soft tissue can sometimes show up more clearly on this scan than on other types of scan. It is a very useful test for soft tissue sarcoma and can show the size and position of the lump.

CT scans

If the sarcoma specialist has told you that you need a CT scan, we endeavour to complete this within two weeks. However if your case is especially complicated this may take longer. In some areas of the body CT scans can give extra information about the size and shape of the tumour and whether it is likely to be a cancer.

A CT scan is a computerised scan using X-rays. You will usually have a CT scan of your chest, abdomen and pelvis to see if there are any signs of sarcoma anywhere else in the body. You may be sent some oral contrast to drink prior to the scan and you may have an injection of dye contrast before the scan. This helps to make the scan clearer to interpret.

DMSA scan

DMSA stands for dimercaptosuccinic acid. A DMSA scan uses radioactive chemicals to create special pictures of the kidneys. These pictures can help doctors assess how well the kidneys are working. DMSA travels through the body joined to a radioactive chemical. It builds up in the kidneys. Pictures of the kidneys are then taken using a special camera which can detect the radioactive chemical. This can be an important test when surgery is being considered. It can take up to two weeks for an urgent DMSA to be completed and longer if it is considered a non urgent test.

PET CT Scan

You may have a PET scan in addition to one of the other tests. During a PET scan you will have an injection of a very small amount of a radioactive glucose, which travels through your body. You then lay under a special scanner like a CT scanner, which shows the levels of glucose in different areas. Cancers use glucose in a different way from normal tissue. This type of scan can show the size of some types of sarcoma and how active the cancer cells may be and also whether they have spread.

Core needle biopsy

A core needle biopsy takes a sample of cells from the lump. The doctor uses a needle with a special cutting tool on the end. You usually have more than one biopsy taken. You will have a local anaesthetic injection to numb the area before the doctor puts the needle in.

If the lump is near the surface of your body and easy to get to, the doctor will probably just feel it to guide the needle in. If the lump is deeper or harder to feel, the doctor will use an ultrasound scan or CT scan to see where the needle is going and guide it to the right place.

The doctor puts the samples of tissue into a small pot. They send them to the laboratory so that they can be examined under the microscope to look for cancer cells.

This procedure can be uncomfortable and your doctor may prescribe mild painkillers for you. If the lump turns out to be non-cancerous (benign) you may not need any more treatment. If it is cancer, your doctor will talk over the treatment options with you.

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Biopsy appointments often start at 07:00. We will try and ensure your biopsy is completed within two weeks, however if the area we need to biopsy is difficult to access, arranging a biopsy can take longer. Once your samples have been sent to the laboratory they will be tested and it can take between 2-4 weeks to complete the specialist tests on the samples needed to assist us with a diagnosis.

You will need blood tests within 2 weeks of the date of the procedure so we may ask you to attend the hospital or your GP for these.

Biopsies are carried out as a day case and can be 1-4 hours, depending on the image guidance used. Further specific instructions will be provided to you once a date has been scheduled.

You won't be able to drive for the rest of the day and shouldn't really be on your own if you are using public transport.

Surgical biopsy

Surgical biopsy means using a surgical knife (scalpel) to open the area and take a tissue sample from the lump. Or, if the lump is small enough, the surgeon may remove it completely. This is called an open biopsy.

Depending on the scale of the biopsy operation, you may have this performed under local anaesthetic or general anaesthetic. Once your samples have been sent to the laboratory they will be tested and it can take between 2–4 weeks to complete the specialist tests on the samples needed to assist us with a diagnosis.

Endoscopy

This is one of the tests we may use if we are concerned you may have a gastro-intestinal stromal tumour. An endoscope is a long, thin, flexible tube with a light and camera inside.

During the test you usually have a sedative to make you drowsy and less aware of what is going on. You may choose to have the test without the sedative. In this case, your doctor will spray your throat to make it numb.

Your doctor or nurse endoscopist will put the tube into your mouth and ask you to swallow it. The endoscope allows them to look at the inside of the gastro-intestinal tract. The images are usually seen on a video screen. They will take tissue samples (biopsies) of any abnormal looking areas. They can do this through the endoscope.

If you have a sedative, you will be drowsy for some time after the test. You can usually go home a few hours afterwards but you will need someone with you.

You won't be able to drive for the rest of the day, because of the sedative, and shouldn't really be on your own if you are using public transport.

We will ensure that this test is done as soon as possible. Once your samples have been sent to the laboratory they will be tested and it can take between 2–4 weeks to complete the specialist tests on the samples needed to assist us with a diagnosis.

Fine needle aspiration (FNA)

FNA means putting a thin needle into the lump to take a sample of cells. If the lump is near the surface of your body and easy to get to, the doctor will probably just feel it to guide the needle in. If the lump is deeper or hard to feel, the doctor may use an endoscopic ultrasound, a regular ultrasound scan or CT scan to guide the needle into the right place.

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The doctor sucks out some fluid from the lump into a syringe. The fluid will contain cells. This procedure is usually no more uncomfortable than a blood test but if you prefer, you can have a local anaesthetic injection before the needle aspiration.

There is normally a 3–4 week waiting list for and endoscopic ultrasound and FNA but we will ensure that it is done as soon as possible.

Once your samples have been sent to the laboratory they will be tested and it can take between 2–4 weeks to complete the specialist tests on the samples needed to assist us with a diagnosis.

Pre-operative tests

Lung function

Lung function tests are used to help the doctor assess how well your lungs are working. They investigate your lung capacity and assess how easily air passes in and out of your lungs. The tests can also determine how efficiently your lungs take up oxygen from the air. This can be important when surgery is being considered as any undiagnosed lung problems can cause unnecessary risks during the surgery so we normally do this test as a precaution. We will try to ensure that this test is completed at least two weeks before your expected surgery.

Echo

An echocardiogram allows us to assess how well your heart is functioning and usually we will only request this test if you are known to have a heart condition or if you are showing signs of a heart condition such as shortness of breath.

This is important if we are considering surgery, as we need to ensure your heart is strong enough to withstand an anaesthetic. We will try to ensure that this test is completed at least two weeks before your expected surgery.

Anaesthetic review

If we think you may have health issues which may affect a decision to proceed to surgery, we may ask our anaesthetic colleagues for a formal assessment. The purpose of this appointment is to assess your fitness for surgery and anaesthesia and provide an assessment of the risks and benefits of the proposed surgery and anaesthesia. It is also an opportunity to confirm that you are fit enough for surgery and still wish to have the operation in the light of these risks and benefits.

Tests for gene changes

Tests that look at the chromosomes and genes in the cancer cells are called cytogenetic tests. Doctors use these tests if there is any doubt about the exact type of sarcoma. They can be useful as some types of sarcoma are treated very differently, for example a liposarcoma may only be treated with surgery whereas a Ewing's sarcoma may be treated with a combination of chemotherapy and surgery.

After the tests

You will be sent an appointment to come back to the hospital, once your test results have come through. Here we will discuss the results with you and plan any subsequent treatment or any further tests required, to help obtain a diagnosis and to plan your treatment.

We understand that you may feel very anxious during this time.

While you are waiting for results it may help to talk to a close friend, relative, your GP or sarcoma nurse about how you are feeling. You may want to contact a cancer support group to talk to someone who has been through a similar experience. Please use the list of organisations overleaf that can put

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you in touch with other people who have cancer, or that provide cancer advice or counselling services.

With thanks to the shared information and ideas from Cancer Research UK.

Sarcoma UK – www.sarcoma.org.uk Tel: 0207 856 0445

GIST UK – www.gistcancer.org.uk Tel: 0300 400 0000

Macmillan Cancer Support – www.macmillan.org.uk Tel: 0808 808 0000

Sarcoma UK Support Line – www.sarcoma.org.uk/SupportLine Tel: 0808 801 0401

Sarcoma West Midlands Support Group – www.sarcoma-westmids.support (currently on hold post pandemic)

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

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

MARSU

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Tel: **0121 371 6648** (always an answer machine)

Email: **sarcomacns.uhb@nhs.net**

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.