



Scans in Neurofibromatosis

A scan creates an image or picture of internal organs of the body such as bone or soft tissue. Scans are used by doctors to help to identify the cause of your symptoms. Your doctor will ask about your symptoms and examine you. Then your doctor may decide to arrange a scan to help determine the likely cause. The scan can help a doctor work out how best to manage or relieve symptoms. Your doctor will decide which type of scan is most appropriate.

Scans are usually performed in a hospital department called Radiology. The doctor in charge there is called a radiologist (a doctor who specialises in the interpretation of scan images). The radiologist is assisted by a radiographer, the professional who carries out the scan and operates the scan equipment.

After the scan has taken place, the radiologist writes a detailed report of their findings, highlighting what they expect would normally be present and describing any abnormalities or unusual findings. Some radiologists are included in the team of NF doctors managing patient care because their skill in interpreting scans is important. These teams of doctors from different specialties are called multi-disciplinary teams or MDT.

The following scans can be used by doctors during investigations for NF:

- Ultrasound and doppler
- Echocardiogram
- Mammogram
- Dexa
- CT or CAT
- MRI
- PET

This information sheet explains about each of these scans in turn.

Ultrasound: what is an ultrasound scan?

An ultrasound scan is a scan that uses high frequency sound waves to create an image of the particular part of the body that is being investigated. An ultrasound scan can examine the organs and structures within the body and help identify potential problems. As it relies on sound waves to produce the images, it is considered safe and there are no risks.

When is an ultrasound scan used?

This type of scan is routinely used during pregnancy to produce images of the developing baby in the womb. It can also be used to detect problems in the heart, abdomen or kidney. In NF it is sometimes used as a first step in identifying a lump or tumour suspected of causing symptoms.

What does an ultrasound scan involve?

An ultrasound scan is painless and takes between 15 and 45 minutes to complete. You will be asked to lie down on a couch and a probe is placed on your skin over the part of the body that is being examined. A jelly is smeared on the skin to ensure a good contact as the probe is moved across the skin. The probe is moved around to ensure that views from different angles are recorded. It is not painful.

What is a Doppler ultra sound?

This is a type of ultrasound that records sound waves off moving objects such as blood flow. It can be used to measure the speed of flow to determine whether this is normal or abnormal. It can identify blockages in an artery or a vein.

Echocardiogram or ECG

Ultrasound scans can be used when checking the health of the heart. An ECG can show whether important structures within the heart are working correctly. It can also show if blood is flowing through the chambers of the heart normally.

Mammogram: what is a mammogram?

A mammogram is an x-ray of the breast. This scan should detect any abnormalities within breast tissue. This includes any evidence of breast cancer. In the UK screening for breast cancer is routinely offered to all women aged between 50 and 70 years.

Women with NF1 should have annual breast screening from the age of 40. At age 50 women will join the national breast screening programme available to all women. You should ask your GP to refer you to the nearest breast screening service to access this service if you are aged 40 and have not already been referred.

Women with NF1 can develop neurofibromas within the breast. In this situation further tests may be necessary to distinguish benign (non-cancerous) neurofibromas from breast cancer. You should always be seen by the breast unit as a first step

A mammogram should not hurt but it may be a bit uncomfortable; this discomfort should settle down very quickly. As with all x-rays a mammogram does involve some exposure to radiation but this is limited. The benefit of early detection of breast cancer is considered to outweigh the risk posed by the radiation exposure involved in the scan.

Dual energy X-ray absorptiometry: what is a DEXA scan?

This is a scan used to assess bone density. It may be used in NF1 to detect bone conditions such as softening of the bones (linked to vitamin D deficiency), bone changes and osteoporosis. These are problems that can be linked to a diagnosis of NF1. The scan result will help the doctor to decide if you need any treatment to strengthen your bones.

The DEXA scan uses x-rays but with a low level of radiation (lower than a normal x-ray). It is not a painful procedure.

Computerised tomography: what is a CT scan?

A CT scan uses a rotating beam of X-rays to produce cross sectional images of structures inside the body. These are displayed on a computer screen for the radiologist to interpret.

During the scan you will be asked to lie flat on a bed, having removed any metal objects such as jewellery, dental braces, your watch etc. You should tell the radiographer (the professional who carries out the scan and is specially trained) if you are pregnant, if you have any allergies or if you cannot lie flat for a long period. A CT scan is painless and the duration will depend on the part of the body that is being scanned, so it may be 15 minutes or longer. The bed that you are lying on will move to different positions so that images can be made from different angles.

A contrast agent (a dye that shows up structures in the body) may be given during the scan. This will be either by an injection or orally (one that can be swallowed). The purpose of the contrast is to enhance the images produced by the CT scan so the picture produced is clearer.

The images produced by a CT scan are detailed. The CT scan can be used to diagnose a variety of health problems such as tumours, some bone conditions, or problems with the heart. It may also be used for guidance if the doctor intends to take a biopsy (a small sample of tissue that will later be examined using a microscope.).

The scan report will be sent by the radiologist to the doctor who requested the scan. This may take a couple of weeks. The doctor will then discuss the results with you.

A CT scan is usually safe but it does mean that you will be exposed to some radiation. Doctors consider that the benefit of the scan outweighs the risk of radiation exposure. This scan is only used where there is a clear need for this investigation.

Children are more susceptible to being affected by radiation exposure than adults and therefore a CT scan is used only when absolutely necessary. Similarly CT scans in pregnancy are not recommended because of risk to the developing baby.

Magnetic Resonance Imaging: what is an MRI scan?

MRI uses magnetic field and radio waves to produce images of the internal organs of the body. A computer converts the information into pictures which the radiologist studies to distinguish between normal and abnormal tissue. MRI can examine areas of the body such as the brain, the spine, the heart, and any area where it is suspected there may be an underlying problem. Sometimes a whole body MRI is performed for people with NF1 that is difficult to manage.

MRI in NF can be used to monitor changes in tissue, to see whether a lump has increased in size, and to assess whether surgery or a drug treatment has been effective.

MRI is painless although it can be noisy.

For an MRI scan you will be asked to lie on a flat bed that is moved into the scanner. A radiographer controls the scanner using a computer. This control room is located separately away from the scanner but the radiographer will be able to talk to you through an intercom. You should tell the radiographer if you cannot lie flat or suffer from claustrophobia or if you think you are pregnant.

You must lie as still as possible during the scan. The duration of the scan varies from 15 minutes to an hour and a half. You can ask the radiographer about this beforehand so you know what to expect. The scanner will make some loud noises. This is normal as the electric current in the scanner coils switch on and off.

You will be offered earplugs or headphones. You must remove all metal objects including jewellery, your watch, coins etc. Some people cannot have MRI because they may have metal implants in their body (for example a pacemaker to control irregular heartbeat). People with NF2 who have an auditory brainstem implant (ABI) can now have MRI with

appropriate preparation. This will be discussed beforehand and the technique of head bandaging explained to you.

Sometimes a contrast dye is given by injection part way through the scan. This helps to show more detail on the scan images.

Children can also have an MRI scan but may find it difficult to lie very still for a prolonged length of time. With very young children an anaesthetic is given to ensure they remain completely still throughout the duration of the scan. It is possible for a relative to remain in the scan room with the patient but that person must also remove all metal objects.

An MRI scan does not involve radiation and is considered to be a safe procedure.

Positron Emission Tomography: what is a PET scan?

A PET scan is occasionally used in investigations in NF using a type of scanner that is only available in large hospitals or in some research centres. In NF a PET scan can be used to establish how fast a lump is growing and how active it is. It may show areas within a lump where the cells are dividing rapidly. PET scans are used to help diagnose cancers and are useful in helping doctors work out the best course of treatment.

PET scanners have a flat bed with a large circular scanner at one end. The radiographer controls the scan from a separate room but will be in communication with you during the course of the scan. You will be asked to lie very still on your back for the duration of the scan. The bed will move slowly through the scanner. It will take about an hour.

You may be asked not to eat or drink (apart from water) for 6 hours before the scan. Further instructions will be available in your appointment leaflet.

At the time of the scan the radiographer will give you an injection that contains a radioactive drug (a tracer). This drug contains a very small amount of radiation. The drug (tracer) will travel through the bloodstream to various parts of the body where glucose is used as an energy source. The scan will focus on lumps that might be growing rapidly. Rapidly dividing cells show up as "hot spots" on the scan. The PET scan helps your doctors to decide if a lump might be cancerous or not and therefore helps them plan further investigation or treatments appropriately.

PET scans do involve radiation but this is considered to be safe. Doctors advise people to avoid close contact with pregnant women, babies and young children for a few hours after the scan to allow any residual radiation to disperse.

How often should I have a scan?

Not everyone with NF will need a scan. It depends on your health and other factors. Scans are not routinely undertaken just because you have a diagnosis of NF. They are an additional tool to help doctors find out about the cause of a symptom or change in how your body is working.

Patients with NF1 may never have a scan if they keep well and have no unusual symptoms that need investigation.

Patients with NF2 routinely have scans to monitor their health. The scan enables the doctors to assess tumours for signs of growth and plan their management accordingly.

The intervals between scans varies and will depend on the judgement of the doctor (s) looking after you. Some NF2 patients who are receiving drug treatment such as Avastin (Bevacizumab for NF2) may need scans at 3-6 months intervals to monitor tumour size during treatment. Other patients may need a repeat scan after 12 months. Your doctor will decide the correct interval.

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