

NATIONAL AMYLOIDOSIS CENTRE

The NHS National Amyloidosis Centre is the only Centre in the UK specialising in amyloidosis and is part of the UCL Centre for Amyloidosis and Acute Phase Proteins. The NHS National Amyloidosis Centre is funded by the Department of Health to provide a diagnostic and management advice service for the UK's national caseload of patients with amyloidosis and related disorders. You have been given an appointment in the outpatient clinic which specialises in diagnosis, quantification and monitoring of amyloidosis. Please find below information concerning your outpatient clinic appointment and further information which may be of interest to you.

BEFORE YOUR APPOINTMENT:

You may eat and drink normally before and after your investigations. You may bring a relative or carer with you to your appointment (preferably only one person), however we would ask that you avoid bringing babies/children or pregnant women where possible.

Attire

Please wear comfortable shoes and clothing, allowing for the top and bottom half of clothing to be removed separately. The wearing of tights and clothes with metallic objects is not recommended. Please do not apply body creams/lotions (except to the face) on the day of the appointment until after the echocardiogram. It is also important to avoid wearing nail polish as this may create difficulties in obtaining certain key measurements with our equipment. Patients having MRI scans will be asked to change out of their clothes and into a hospital gown, and remove all metallic objects such as jewellery, belts, keys, coins, etc.

Doctors' details

Please update as necessary the contact details for all the doctors (GP and consultants) currently treating you on the enclosed sheet. Please give this to the receptionist on your arrival at the National Amyloidosis Centre.

24 hour urine collection

A 24 hour urine collection for protein analysis may be required. If so, we will include instructions with your appointment letter.

Medication

Continue taking your current medication. Please bring a list of medications/dosages and carry it with you at all times during your visit.

Pregnancy

We **cannot** inject you with the radiation to perform the SAP scan or DPD scan if you are, or suspect you are pregnant. If there is any doubt we will perform a pregnancy test before the injection, as is our policy for all female patients between 12-55 years of age.

Please inform us if:

- You are allergic to iodine, or anything else that you know of
- You may be pregnant
- You have a pacemaker
- You have hearing implants or an aneurysm clip
- You have small pieces of metal in your eye (e.g. from welding)
- You have limited mobility (please ensure, if possible, that you are accompanied)
- You need an interpreter (request this in advance, or arrange for a friend/relative to attend the consultation)

WHAT TO EXPECT AT YOUR VISIT:



Please arrive at least 15 minutes before the time shown in your appointment letter. This is extremely important on the day of your scan as slots are limited and timings are tight.

Below is a summary of the procedures that we routinely carry out – however, it is important to note that not all patients require every one of these procedures.

1. ECG and echocardiogram

The echocardiogram is an ultrasound of the heart. It is performed to look for amyloid deposits in the heart. It takes about 45 minutes and is carried out in the echocardiography suite within our Centre. We will also do an ECG just before (or after) the echocardiogram.

2. Blood tests and radio-isotope injection

The clinic nurse will use a small needle to draw some blood for a range of tests. A small amount of radiolabelled human SAP protein (highly purified from blood) or radiolabelled DPD (a commercially available ‘bone’ tracer) may then be injected via the same needle. The SAP protein has been extensively screened and undergone virus removal and inactivation procedures.

3. Six minute walk test

This test is used to evaluate your exercise capacity. It measures the distance that you can walk, quickly, on a flat, hard surface in a time period of 6 minutes. The clinic nurse will take you to a hallway in our department which is free of obstacles and instruct you to walk up and down and cover as much ground as possible over 6 minutes. You should walk continuously if possible, but should not be concerned if you feel the need to stop and rest or slow down. The goal is to feel at the end of the test that you could not have covered more ground in 6 minutes. If you need physical assistance from another person in order to walk then you need not perform this test. If you usually walk with the assistance of a device such as a walking stick or frame, you may use this. The nurse will document the use of an assistive device and you should use the same device each time you do this test.

4. SAP scan

This scan is performed either the day after or 2-3 hours following the injection of the radiolabelled SAP protein and takes about 30 minutes. You will be asked to lie on the scanning bed and remain still whilst the scan is being performed. It is not an enclosed 'tunnel' scanner but is nonetheless, positioned quite close to you so as to get the best quality images. You will not feel any discomfort or experience any loud noises during the scan. Please drink normally between the injection



and the scan (adhering to any fluid restriction that has been imposed). You will be asked to empty your bladder before the scan. Feel free to bring a CD or personal music device to listen to during the scan.

5. DPD scan

Unlike the SAP scan, the DPD scan (also performed at the NAC) can be used to investigate amyloid deposits in the heart. We may request that you also undergo a DPD scan during your assessment which involves the injection of a different radiotracer (called ^{99m}Tc-DPD). The DPD tracer will be injected into a vein in your arm and the scan will be performed 3 hours later. In between, you can eat and drink as normal. The scan lasts approximately 1 hour and consists of a scan of your whole body followed by a 3-Dimensional scan of your heart including a small CT scan. Feel free to bring a CD or personal music device to listen to during the scan. You will need to lie down on the open scanner and remain as still as possible during the scan. Please note that your DPD and SAP scans cannot be performed on the same day and we may therefore need to make another appointment for you to come back to have the DPD scan.

6. MRI scan

MRI scans can provide additional helpful information in some cases and we may request that you undergo a CMR (Cardiac Magnetic Resonance Scan) during your appointment. A CMR scan uses a strong magnetic field and radio waves to create detailed images of your heart. It gives us information on the structure of your heart and blood vessels and how well they are working.

We will ask you to lie on a bed that will slide into the scanner. You will need to lie as still as possible and to hold your breath for approximately 8 seconds while we take each image. This stops your chest from moving and ensures that our images are as clear as possible. During the scan we will use a contrast agent to get more information on the tissue composition. This is a colourless liquid that we can inject into a vein in your arm enabling us to see your heart and blood vessels more clearly.

7. Implantable Loop Recorder

During your first visit to the Centre, you may need to have a 'Loop Recorder' placed just under the skin. This device, which is the size of an AA battery, is used to identify abnormal heart rhythms which may need treating and which may occur intermittently whilst you are at home.

8. Consultation

You will see one of our specialist doctors for a consultation. Please note that all our doctors work as a team and you will be seen by whoever is on duty for that clinic. Nonetheless, your case will routinely be discussed at our multi-disciplinary meeting which is attended by all doctors from the Centre. Please be prepared to be flexible with your time throughout your visit here, as delays or changes can occur.

USEFUL CONTACTS AT THE NATIONAL AMYLOIDOSIS CENTRE

If you have any queries about your visit, please do not hesitate to contact the following people:

Reception+44 (0)20 7433 2725

- Blood bottle requests
- General enquiries

Unit Secretaries+44 (0)20 7433 2737/2798/2811

- Information on clinic letters/medical reports
- To contact one of our doctors
- General enquiries

Appointments+44 (0)20 7433 2813

- To book, cancel or reschedule an appointment

Administrative Support Officer+44 (0)20 7433 2812

- Blood results
- Patient transport and accommodation
- Overseas and private patient arrangements

Clinic Nurses+44 (0)20 7433 2738/2730/2799

- Medical queries

Our opening hours are 7.45 am to 5.30 pm Monday to Friday.