

## What to expect at your appointment

Below is an example of some of the tests you may encounter depending on where you are being evaluated at your appointment. We have put this together as general guide for you.

### WHAT TO EXPECT AT YOUR VISIT

Below is a summary of the procedures that you may encounter – however, it is important to note that not all patients require every one of these procedures or tests

#### 1. 24 HOUR URINE COLLECTION

A 24-hour urine collection for protein analysis may be required.

#### 2. Vital Signs and ECG

- a. Height, weight, blood pressure, heart rate, and oxygen saturation
- b. Orthostatic vital signs in lying, sitting and standing position
- c. Electrocardiogram

#### 3. Blood Tests

The phlebotomist will use a small needle to draw blood for tests.

#### 4. Echocardiogram

The echocardiogram is an ultrasound of the heart. It takes approximately 60 minutes and is used to evaluate cardiac structure and function.

#### 5. X-ray and CT scan/MRI

You may undergo an X-ray of the chest. Other scans and MRI are performed based on clinical assessment.

#### 6. Tc 99mPYP scan

This is a non-invasive scan of the heart used to diagnosis transthyretin amyloidosis.

#### 7. Pulmonary Function Test

This test is to check your lungs. Lungs and functional status that is usually only completed on new patients or patients with pulmonary amyloidosis. Testing consists of two parts including an exercise portion.

#### 8. Bone Marrow Biopsy

This test is only performed on patients with light chain or suspected light chain amyloidosis - if you had a bone marrow recently please make sure the provider has a copy of the results.

## **Suggested Questions to ask your Doctor**

- Have you treated many patients with amyloidosis?
- What proof is there that I have the type of amyloidosis I am told I have?
- Why do you think the treatment you are suggesting will help me?
- What exactly is the treatment and what does it do?
- Will this slow my disease or cure it?
- Will the treatment make me sick?
- How have other patients found this treatment?
- How will you know if the treatment is working and what are the tests that indicate this?
- What happens if the treatment does not work or upsets me?
- Why is there little treatment for my type of amyloidosis?
- Can I work?
- How can I help myself?
- What information about my disease do you recommend?
- Can I meet other patients with my type of amyloidosis?