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Alnylam Amyloidosis Connect

Guidance for the referral of patients with amyloidosis to the National Amyloidosis Centre (NAC)

Helping your patients get the specialist care they need

Amyloidosis is rare and can affect many organ systems, so early referral to a specialist centre can make a real difference for your patients. Catching it early helps prevent irreversible organ damage and optimise patient outcomes.

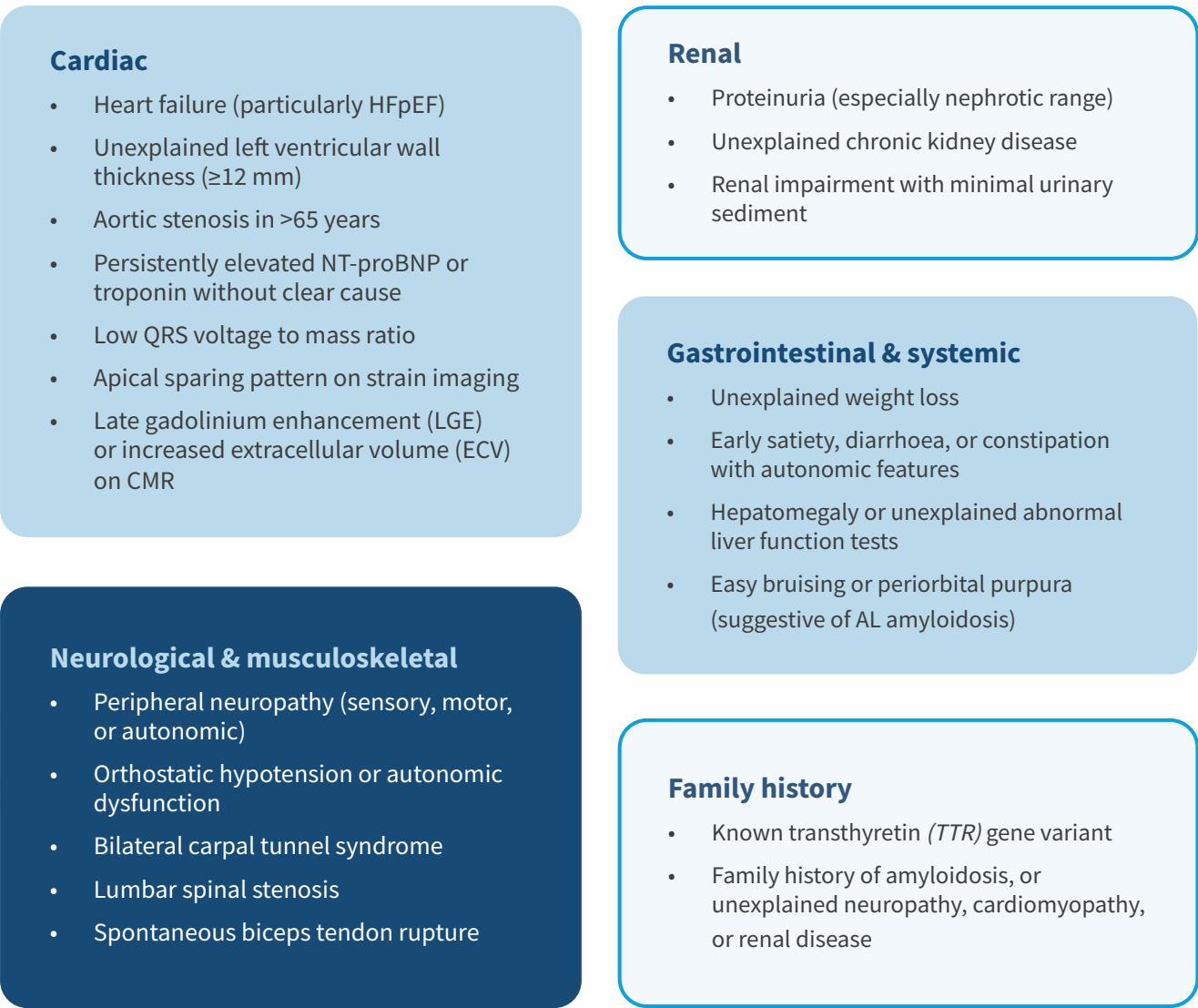
While local teams continue to provide routine patient management, the NAC offers specialist assessment, multidisciplinary team (MDT) review, and shared-care guidance.

This document provides a clear, step-by-step referral pathway for healthcare professionals to facilitate timely and appropriate referral to the NAC.

Recognising possible systemic amyloidosis¹

Amyloidosis often presents with non-specific symptoms and may involve more than one organ system. Suspicion should increase when otherwise unexplained features occur together.

Clinical features that should raise suspicion



Please note this is not an exhaustive list
Multisystem involvement should prompt consideration of systemic amyloidosis.

If these features are present and amyloidosis is suspected:^{1,2}

- Arrange diagnostic testing in line with the diagnostic algorithm
- If the recommended diagnostic tests cannot be performed locally, please consider early referral to the NAC

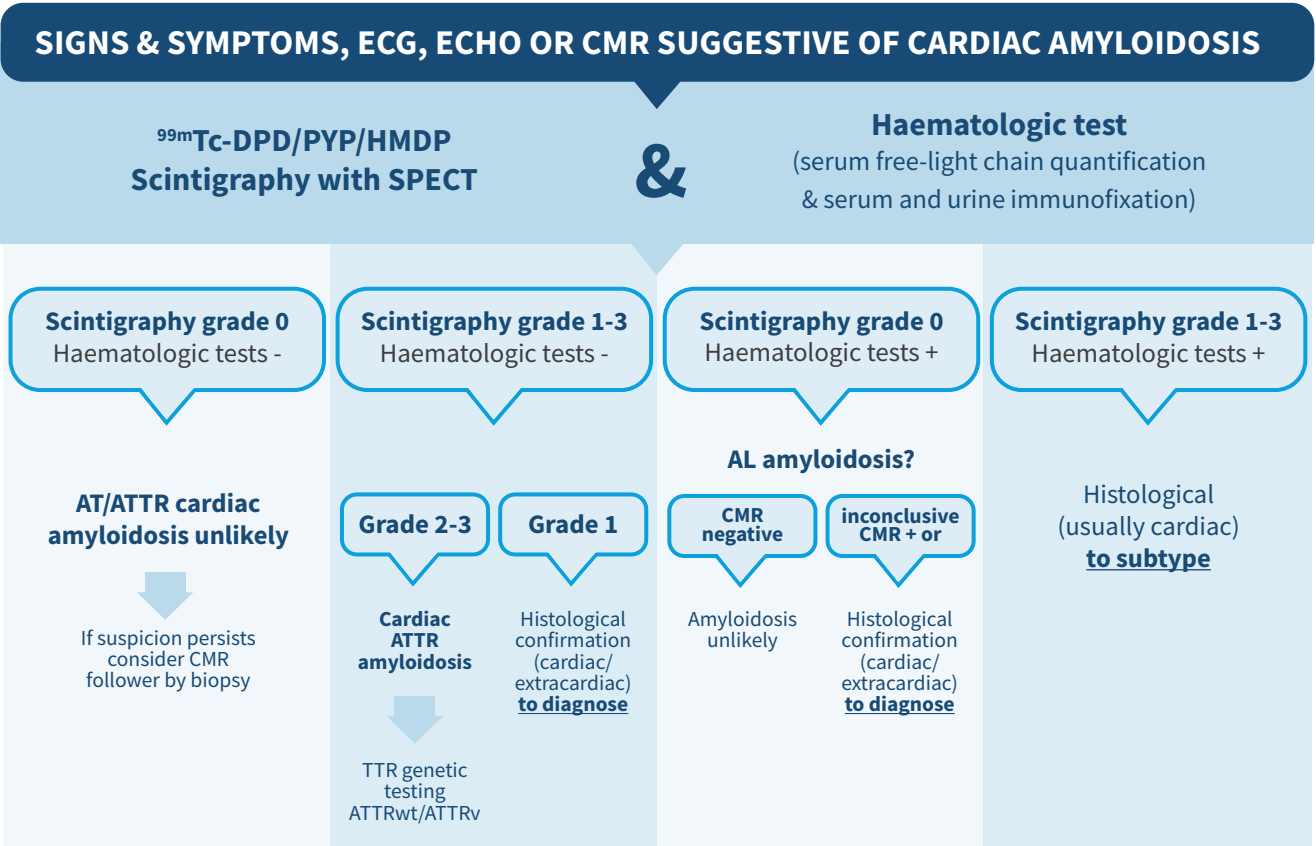
Early recognition and prompt action are crucial to enable timely diagnosis and access to disease-specific treatment.

Example diagnostic pathway: when cardiac amyloidosis is suspected (AL and ATTR)¹

When cardiac features raise suspicion of amyloidosis, the ESC-recommended diagnostic pathway below helps identify both AL and ATTR cardiac amyloidosis and supports early, appropriate referral. This pathway does not replace specialist assessment but helps ensure the right initial tests are performed.

ESC diagnostic algorithm for suspected cardiac amyloidosis

Combines bone scintigraphy with monoclonal protein testing to differentiate ATTR from AL amyloidosis and determine when biopsy is required.



Adapted from Garcia-Pavia P, *et al.* 2021.

Important: Many patients with ATTR cardiac amyloidosis can be diagnosed without biopsy by using bone scintigraphy (DPD/PYP/HMDP) together with blood and urine tests to exclude a monoclonal protein. If a monoclonal protein is detected, AL amyloidosis must be urgently excluded and referral should not be delayed.

If cardiac amyloidosis is suspected or confirmed at any stage in this pathway, early referral to the NAC is recommended for specialist assessment and shared-care guidance. The following section outlines when and how to refer.

1 When to refer¹

You should consider referring a patient to the NAC if they have any of the following:

Suspected or confirmed systemic amyloidosis (AL, ATTR, AA, or other)

Unexplained organ dysfunction (cardiac, renal, hepatic, neuropathic) suggestive of amyloid disease

Hereditary amyloidosis or a known amyloid gene variant

Family history of amyloidosis requiring genetic counselling

Confirmed amyloid on biopsy where typing or staging is required

Note: Referral does not replace ongoing local care; the NAC acts in a shared-care and advisory role.

2 Preparing the referral² Required information

To help the NAC see your patient quickly, please include the following information in your referral:



Patient identifiers

Full name, date of birth, NHS number, full address and contact telephone/email



Referring clinician details

Name, specialty, hospital/clinic, contact telephone/email

Core clinical information

- **Brief summary of symptoms and the reason for referral** (eg. weight loss, neuropathy, heart failure, bicep tendon rupture, nephrotic syndrome)
- **Suspected organ involvement** (cardiac, renal, hepatic, neurological, gastrointestinal autonomic)
- **Relevant medical history** including prior and current treatments/interventions (eg. chemotherapy, anti-inflammatory therapy, breast-conserving therapy, organ transplantation, other specialist therapies)
- **Family history;** For hereditary amyloidosis or transthyretin variants, include details of any affected relatives if known (name, date of birth, hospital, and gene result if available)

Key blood tests

(Recent results, ideally within the last 3 months)

- Renal profile (eGFR, creatinine, urea, electrolytes)
- Liver profile (ALT, AST, ALP, bilirubin, albumin)
- NT-proBNP

Essential haematology tests required for suspected AL (light-chain) amyloidosis

- Serum immunofixation
- Urine immunofixation (24-hr or spot sample)
- Serum free light chains (kappa, lambda, ratio)

Electrophoresis alone is not sufficient

Cardiac investigations

- ECG
- Echocardiogram
- Cardiac MRI (if performed)
- DPD/PYP cardiac scintigraphy (if available)

Attach full reports, including the date and location of testing.

Other investigations

- Renal biopsy report (if performed)
- Neurology assessments (if neuropathy suspected)
- Genetic testing results (if hereditary amyloidosis is suspected) provided in full if testing was not completed at the NAC

Pathology

- Histology and immunohistochemistry reports if amyloid has been detected
- Where possible, send tissue blocks/unstained slides for NAC review

3 Referral submission & triage²

Referrals should be submitted electronically but may also be submitted by post if this is not possible.



Electronic

Secure NHS email to:
rf-tr.amyloidosis-admin@nhs.net



Postal

National Amyloidosis Centre,
Royal Free London NHS
Foundation Trust, Pond Street,
London NW3 2QG

Access the NAC
referral proforma here
(non-Alnylam owned link)



The team at the NAC will prioritise urgent referrals to make sure patients get seen at the right time. This includes patients with urgent needs such as advanced cardiac involvement, severe organ dysfunction or AL. If you would like to speak to the NAC directly to discuss a patient, please call them on **0207 433 2800**.

Note: The NAC does not provide emergency or general secondary-care services; local teams remain responsible for chemotherapy and acute care.

4 What to expect after the referral^{2,3}

Appointments and investigations: The NAC will schedule the patient for consultation and, where required, specialist investigations. These may include scans, laboratory tests, biopsies, and genetic testing and are typically completed over 1–2 days

Triage and consultation type: Where a diagnosis has already been established prior to referral, patients may be triaged to a telephone consultation, which can significantly reduce waiting times. If required diagnostic tests are not available locally, referral to the NAC is encouraged.

MDT review and reporting: The MDT at the NAC reviews each case and provides a detailed written report, including diagnosis confirmation and a management plan, to the referring clinician.

Shared-care model: Ongoing care is delivered through a shared-care approach between the NAC and the local specialist team.

Follow-up: Follow-up is typically arranged every 6–12 months, depending on the type of amyloidosis and treatment pathway.

5 Key points to remember^{2,3}



Early referral can change outcomes

Given the potential for organ damage, timely specialist input is crucial



Maintain local care

Referral to NAC does not replace your role; you remain central to patient monitoring and management within your service



Complete referrals optimise triage

A detailed referral speeds up assessment and prioritisation – please ensure you include all required information outlined in [section 2](#)



Be aware of hereditary implications

For ATTR and other hereditary amyloidoses, genetic counselling is integral to the pathway



Communicate with patients

Explain the purpose of the referral, the possibility of remote prescribing and avoiding travel to London if all required tests and paperwork are provided, and how the shared-care model would operate



Ready to refer?

Do you feel confident and prepared to refer a patient? If you encounter someone with suspected or confirmed systemic amyloidosis (or a family history of a hereditary form) now is the time to act and initiate referral to the NAC without delay.

Complete the referral form/letter with the information outlined above and send it directly to the NAC.

Your timely action can make a real difference.

To contact the NAC clinic co-ordinators directly call **0207 433 2800**
or email rf-tr.amyloidosis-admin@nhs.net (general)
or rf-tr.amyloidosisappointments@nhs.net (appointments)

References:

1. Garcia-Pavia P, *et al.* Eur Heart J. 2021;42(16):1554–1568.
2. National Amyloidosis Centre. Information for Referring Physicians. Available at: <https://www.ucl.ac.uk/medical-sciences/divisions/national-amyloidosis-centre/information-referring-physicians>. Accessed May 2026.
3. NHS England. NHS STANDARD CONTRACT FOR DIAGNOSTIC SERVICE FOR AMYLOIDOSIS. Available at: <https://www.england.nhs.uk/wp-content/uploads/2013/06/e13-diag-serv-amyloidosis.pdf>. Accessed May 2026.