

Build locally. Connect nationally. Treat remotely.



Alnylam Amyloidosis Connect

Expanding amyloidosis care in your region

**Could you help to build
a team that changes
outcomes for patients?**

As a clinician who is involved in caring for patients with amyloidosis, we thought you'd like to learn more about multidisciplinary collaboration and whether it could be implemented in your practice.

This guide has been developed by Alnylam with input from UK clinicians involved in and supporting multidisciplinary teams (MDTs) for amyloidosis. It provides practical advice on establishing your own team and outlines the potential benefits for your region and helps you assess whether the necessary expertise, infrastructure, and support are in place to run one successfully.

Why is your help needed?

Early and accurate diagnosis is vital in amyloidosis, as even short delays could impact outcomes. Strengthening care through new regional MDTs will improve access to specialist input and help deliver timely, effective treatment across the country.

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Disease modifying treatment works best if started early in the disease course

Marianna Fontana,

Professor of Cardiology and Honorary Consultant Cardiologist at the National Amyloidosis Centre (NAC)

This is where your role becomes vital.

Amyloidosis often presents across multiple specialties – cardiology, nephrology, haematology, neurology – making it difficult for any single team to manage effectively. Your expertise and collaboration can help ensure patients are recognised sooner, referred appropriately, and receive the co-ordinated, timely care they need.

By helping set up MDTs, you could help centres work together to:



Enable earlier diagnosis, improving patient outcomes



Provide timely, co-ordinated care closer to home



Reduce the need for patients to travel long distances



Share the workload of diagnosing and managing amyloidosis



Collaborate through shared protocols, virtual meetings, and clear referral pathways

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The current diagnostic delay is the #1 priority; we need to work together to reduce it

Marianna Fontana,

Professor of Cardiology and Honorary Consultant Cardiologist at the National Amyloidosis Centre (NAC)

Assessing your region's readiness for an MDT

Before taking steps to set up an MDT, you need to first ensure the necessary capabilities are in place for the team to work effectively. These may be available within your own centre, or you may consider collaborating with other centres in your region to meet the requirements of an effective amyloidosis service.

1 Explore your core team



Identify the key specialists – either within your centre or across the wider region – who are needed to provide co-ordinated care.

Bear in mind that the MDT can start small, with just the core specialists, and expand over time. Members can also join remotely as needed to ensure fully co-ordinated care.

Core team (essential to start an amyloidosis MDT):

- Cardiologist
- Haematologist

Optional team members (flexible involvement):

- Nephrologist
- Neurologist
- Radiologist
- Pathologist
- Pharmacist
- Geneticist
- Nuclear medicine physician

Note: Efficient MDT functioning can benefit from support from central administration departments. While not part of the clinical core team, these roles help ensure timely and organised care.

2 Check your core resources



Core team members can help assess whether you have access to the right equipment to diagnose patients accurately, make decisions quickly, and ensure everything runs smoothly.

Essential diagnostic tools:

Cardiac imaging
(ECG, CMR, ECHO)

DPD bone
scintigraphy

Lab support for light chains, serum/urine
electrophoresis & immunofixation

Biopsy co-ordination and **Congo red staining** (including bone marrow, renal, and all other relevant biopsies)

TTR genetic
testing

Virtual meeting platform for case
discussion



Ready to make the first move?

If your centre has access to the necessary resources and you're ready to advance amyloidosis care, you're in a great position to make this MDT a success – and you don't have to do it alone. Our team is able to support you throughout the process. Alnylam can connect you with practical tools, resources, and proven best practices to help deliver timely, co-ordinated care.

If your team does not yet have all the assets in place but you are still interested to discuss your case, don't worry – Alnylam can link you to the closest MDT centre to your hospital.

Not sure where to start?



Take a look at our step-by-step **How-to Guide**, which walks you through setting up your MDT. You can also reach out to Alnylam directly at amyloidosisconnect@alnylam.com whether you'd just like to connect, or want more detailed information.

More details are also available on the NAC website (non-Alnylam owned site):
www.ucl.ac.uk/medical-sciences/divisions/national-amyloidosis-centre/information-referring-physicians