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Alnylam Amyloidosis Connect

Improving outcomes for
patients with amyloidosis
through coordinated care

Your guide to establishing an effective amyloidosis multidisciplinary team

As amyloidosis care becomes increasingly complex, co-ordinated expertise across multiple specialties is more important than ever. By setting up a multidisciplinary team (MDT) in your region, you are taking a key step toward providing high-quality, patient-centred care for people living with amyloidosis.

This guide has been developed by Alnylam with input from UK clinicians involved in and supporting multidisciplinary teams (MDTs) for amyloidosis. It walks you through the steps needed to set up an effective MDT. Whether implemented within the team, or by an assigned co-ordinator, by following the responsibilities laid out in this guide you will be on your way to ensuring smooth, co-ordinated care for your patients.

STEP 1

Define the purpose and scope of your amyloidosis MDT

Clarifying your MDT's purpose and scope from the offset helps you to give your team a clear focus.

This crucial first step helps you define how the team will operate, keeps everyone aligned on shared goals, and ensures everyone knows exactly which patients and services your MDT will cover.

Keep in mind that your MDT's purpose will depend on the types of patients you treat, the population you serve, and the services available to you.

Common objectives of an amyloidosis MDT include:



Supporting early identification and diagnosis



Co-ordinating timely, effective treatment plans



Managing complex cases with specialist input



Collaborating in research and clinical trials



Monitoring outcomes and quality of care

Note that the scope of your MDT can vary greatly depending on your setting, resources, and goals.

Factors to consider:

The capabilities of your team (eg. breadth of specialties involved)

Your typical caseload (local/regional centre vs. specialist hub)

The level of service provided (eg. part of the pathway or the full patient journey)

STEP 2

Identify and recruit your team members

Your MDT is strongest when it brings together the right expertise.

Start with the key specialists needed to diagnose and manage amyloidosis, and add other team members from your centre or the wider region when possible to build a team that can deliver meaningful improvements in patient care.



Core team (essential involvement):

- Haematologist
- Cardiologist

Optional team members (flexible involvement):

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



Once your team is identified, it's important to build momentum by highlighting the shared benefits of the MDT.

By ensuring every member knows their role and is committed to regular meetings, you turn a talented group of specialists into a truly effective team.

STEP 3

Planning is the key to success

Taking the time upfront to get the logistics right will help you set your team up for success, ensuring everything runs smoothly right from the start.

Key actions and considerations:



Set a rhythm for regular MDT meetings



Decide a meeting format – in-person, virtual or hybrid (whatever works best for your team); allow 1–2 hours per meeting



Assign a chairperson – often from cardiology or haematology, to lead and drive meetings



Appoint a co-ordinator (if possible) – a nurse or administrator to manage referrals, collate documents, and prepare agendas



Share new referrals with the team ahead of each meeting so that the team are familiar with the patient when they are discussed in the MDT



Use a **standardised meeting agenda** – covering new referrals, case presentations, diagnostic reviews, treatment planning, follow-ups, research updates, operational items, and a clear summary of decisions and action points



Record outcomes using a mutually accessible document



Tip:

To make things easier, we've included a ready-to-use template for your first meeting agenda



STEP 4

Build your clinical workflow

With a clear, well-planned workflow, you can help keep your team organised and efficient, prevent duplication of effort, and ensure that patients progress smoothly through diagnosis, treatment, and follow-up.

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We recommend using a standard referral document that you can share with the wider team upfront for consistency in your MDT pathway.

Dr Francesco Rainone,
*Clinical Lead for MGRS & Pan-Manchester Amyloidosis
MDT Lead*

Remember, your MDT won't be working in isolation – there will be important touchpoints with the National Amyloidosis Centre (NAC) that can provide support, guide patient care and ensure access to treatment.

While we'll share detailed guidance on working with the NAC on the next page, it's worth beginning to think about how these connections will fit into your pathway.

Key actions and factors to consider



Create clear, concise referral criteria

Define which patients should be referred to the MDT based on diagnosis, symptoms, or organ involvement.

Examples include:

- Suspected amyloidosis based on clinical red flags (eg. unexplained HFpEF, proteinuria, neuropathy)
- Biopsy-proven amyloidosis needing subtyping
- Complex multi-organ cases
- Include urgent referral pathways for high-risk cases



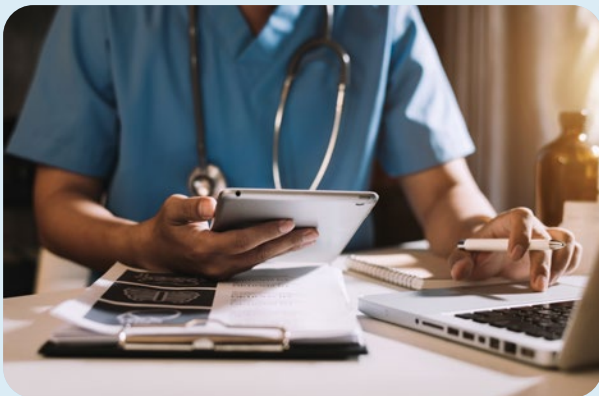
Standardise the requirements for referral



Scan to download the NAC treatment request form (non-Alnylam owned form).

You can also provide templates outlining the essential information and investigations to accompany each referral:

- Clinical summary (including previous treatments)
- Relevant imaging (CMR, SAP scan, ECG, ECHO)
- Renal and bone marrow biopsy reports (Congo red staining, IHC, or mass spectrometry)
- Laboratory results (serum free light chains, serum and urine immunofixation, troponins, NT-proBNP)
- ECG and EMG if neuropathy is suspected



Seeing the clinical images first-hand allows specialists to make better-informed decisions than relying on reports

Dr Robert Cooper,

Consultant Cardiologist Liverpool Heart and Chest Hospital



Develop standardised clinical protocols

Covering initial assessment, diagnostics, and treatment planning, including:

- Diagnostic algorithms for AL and ATTR amyloidosis
- Cardiac, renal, and neurological monitoring schedules
- Referral pathways for ATTR treatments
- Chemotherapy regimens and supportive care guidelines
- Genetic testing and counselling pathways for hereditary amyloidosis
- Enrolment in clinical trials (when available)
- Streamline MDT discussions – Consider using checklists or proformas for case presentations to keep meetings focused and decisions clear
- Plan for ongoing care – Ensure protocols include follow-up schedules and criteria for re-referral or escalation

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It's important to clearly define who is presenting each case. If the patient is being managed locally, the responsible clinician should ideally attend; otherwise, with agreement the case details can be shared with the amyloidosis team and the chair can present on their behalf.

Dr Robert Cooper,

Consultant Cardiologist Liverpool Heart and Chest Hospital

Next steps to start building your amyloidosis MDT

You don't need to do everything at once – you can start with the steps below, and build up from there.



Draft a proposal

Outline the purpose, scope, and structure of your regional amyloidosis MDT



Start the conversation

Share your proposal with potential team members to start getting them on board



Schedule your first MDT meeting

Set a date, share an agenda, and start building momentum



Develop a referral form and proforma templates

Standardise the information needed to make discussions efficient and decisions clear

Setting up a regional MDT for amyloidosis doesn't have to be complicated, but it can have a huge impact. With shared commitment and a clear framework, you and your team can deliver more co-ordinated, effective care for patients across your region.



Remember, we're here to help

You're not alone, but helping this underserved patient group relies on people like you taking the first step and starting the initial conversations about setting up MDTs.

At Alnylam, we can support you in providing guidance, resources, and access to relevant networks. Like you, we are committed to improving outcomes for patients with amyloidosis. To explore how we can be involved, please get in touch with us at amyloidosisconnect@alnylam.com

