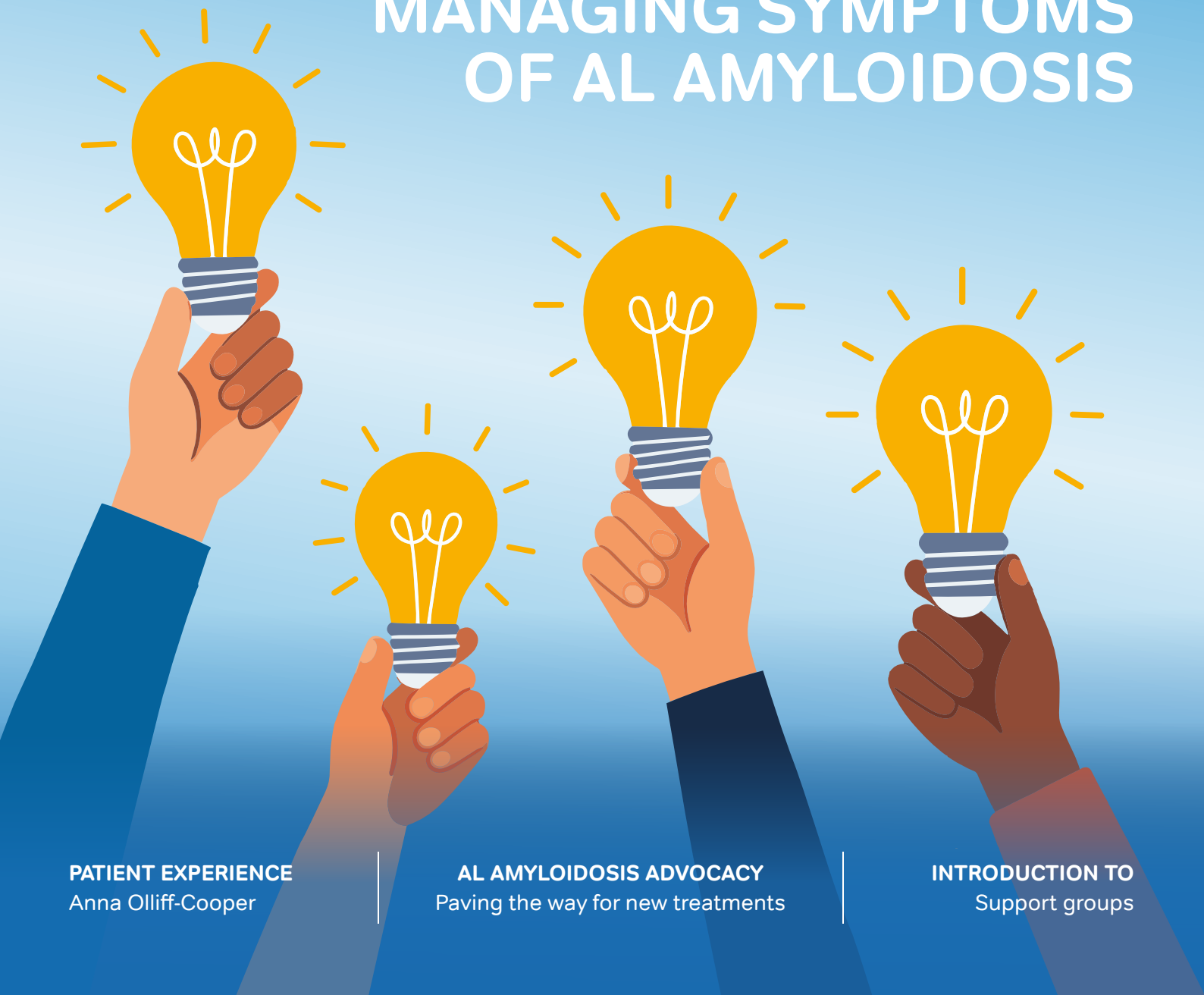
MyelomaUK

AL amyloidosis Matters

Issue 25 Winter 2025

HOT TOPIC

TOP TIPS FOR MANAGING SYMPTOMS OF AL AMYLOIDOSIS



PATIENT EXPERIENCE
Anna Olliff-Cooper

AL AMYLOIDOSIS ADVOCACY
Paving the way for new treatments

INTRODUCTION TO
Support groups

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Paving the way for new treatments

Welcome!

Welcome to this edition of AL amyloidosis Matters.

I am delighted to be stepping into the role of Editor for AL amyloidosis Matters. My hope is that this magazine continues to be a space where our readers and wider community can find inspiring stories, practical information, and a sense of connection.

In this edition, we meet Anna, who shares her honest experience of being diagnosed with AL amyloidosis and myeloma. As a retired GP, she describes the challenges she faced in discussing her symptoms with her own doctor and gives her personal reflections on looking ahead with hope.

Many readers may not know that our Myeloma Information Specialists support not only those affected by myeloma, but also anyone affected by related conditions, such as AL amyloidosis. Our Infoline and Ask the Nurse email services are available to patients, family members, friends, and carers. On page 8, you'll find answers to frequently asked questions from our team, along with details on how you can get in touch.

We often hear from people seeking advice on managing symptoms and treatment side effects. That's why our Hot Topics section takes a closer look at this, featuring practical tips from our community and trusted health sources. Turn to page 6 to learn more.

Support following a diagnosis of AL amyloidosis can make a real difference. Support groups offer comfort, community, and shared understanding. If you are interested in joining a group, or even starting one in your area or online, you can find helpful information on page 9.

As always, we welcome your feedback and suggestions for topics you would like to see covered in future editions of AL amyloidosis Matters. If you or someone you know would like to share a personal story, we would love to hear from you.

From everyone at Myeloma UK, we wish you all the best for the rest of 2025 and into 2026.

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MY LIFE WITH **AL AMYLOIDOSIS**

NAME: Anna Olliff-Cooper

LIVES: Winchester

AGE: 76

I'm a retired GP, and back in January 2024 I was diagnosed with myeloma and cardiac amyloidosis.

My symptoms started a bit over two years before my diagnosis. I had parked too close to a wall, and had to squeeze through the car door, and fractured a rib. The following summer, I got an odd pain in my right buttock area that my GP thought might be a sprain from running. I would probably have made the same diagnosis.

Then I got a chest infection, and a few months later I leant forward to take something out of the washing machine with a slight twisting motion and broke another rib. I had another chest infection and started feeling increasingly tired. I used to be able to work the whole day, but now I was finding I needed to sit down by mid-afternoon. Soon I needed to sit down by lunchtime.

I noticed other funny things going on. I was getting some very odd mouth ulcers, which were there one minute and then gone a few hours later. There were odd marks under my fingernails, and my tongue looked as if the edge had been pushed in by a finger, creating a scalloped appearance all the way round. I looked that up, and it said this can just occur in old age.

I thought, I can't go to my own doctor and say, 'I think I've got a funny-looking tongue'. They are far too busy, and anyway each of my symptoms could be explained by just getting older.

I got another chest infection with shortness of breath. So, reluctantly, I did go back to my GP and said, 'I've got this odd feeling in my chest, I'm short of breath. I used to be able to walk 10 miles and run 3 times a week, but now I can't walk up a simple incline'. She listened to my chest, didn't look particularly concerned and asked if I had any chest pain. I didn't really, but she ordered an ECG. I can remember the change in her expression when she came back into the room with the ECG in her hand.

> **"Back home I got worse week by week, almost day by day."**

She said: ‘Well, something's certainly going on. Your ECG has changed markedly from when it was done last, so I'm sending you into hospital in case this is a silent heart attack’.

It wasn’t a heart attack, but I was kept in hospital for 10 days, having this test and that test. Eventually they said there didn’t seem to be much wrong, just a bit of a mildly leaking heart valve. I could go home and have a follow-up in cardiology out-patients.

Back home I got worse week by week, almost day by day, so I arranged to see a cardiologist privately. He referred me to a cardiac surgeon who said I now had two leaking heart valves and booked me in for open-heart surgery to replace or repair them.

Then, 2 weeks before surgery, he said he wanted just one more scan – a cardiac MRI – which flagged up the possibility of cardiac amyloidosis.

But before that result came through, I became so weak I could no longer get up the stairs. I live alone and just couldn’t look after myself.
I sent out an SOS and my best friend, who is also a doctor, turned up and took me back to hospital. Her last words were: ‘Do not, on any account let them discharge you, something is really wrong’.

“I also wish I had told my GP about all my other weird symptoms and not thought, ‘Oh God, they're going to think I’m completely neurotic’.”

Being told my diagnosis was a big shock. Myeloma hadn’t crossed my mind, let alone cardiac amyloidosis. I didn't have any of the normal markers for myeloma – no anaemia, high calcium, kidney impairment or raised inflammatory markers. All I had was this odd pain in my buttock.

In retrospect I'm kicking myself that I didn't go back to my GP about this pain, which had been quite persistent and bad enough to keep me awake at night.

If I had, perhaps I would have had an MRI of my hip then, which would have uncovered the holes in my pelvis caused by the myeloma, and got me into treatment before so much damage had been done to my heart.

I also wish I had told my GP about all my other weird symptoms and not thought, ‘Oh God, they're going to think I’m completely neurotic’. Because, although all the odd signs I had noticed with my nails, tongue and the mouth ulcers, sounded trivial individually, combined they added up to something that needed further investigation.

I found the treatment very difficult. By the time I was diagnosed I was in stage 3B cardiac failure, which comes with a particularly poor outlook. I was told that if I got through chemotherapy, I might look forward to maybe 9 months’ survival.

Thankfully, I’ve been lucky. The abnormal proteins in my blood fell to normal within a matter of days and have stayed there for the last 18 months. But treatment made my heart failure much worse.

I couldn't lie flat or even lean back because I felt so short of breath. I couldn't complete whole sentences without stopping to breathe.

I was told nothing much could be done about this as, once the amyloid has lodged in the heart, there was no way of getting it out. However, after a couple of months my heart started to improve spontaneously and has gone on doing so, to the point that I no longer need valve surgery.
From not being able to look after myself, I am now back to walking on the flat and full independence.

“Life is not the same, but it is still good.”

I can't look too far into the future. I have to plan my life in the 10-week blocks between one consultant appointment and another, but I try to make the most of each block. My son was due to get married 6 months after I started chemotherapy, and I saw that, albeit from a wheelchair and courtesy of an extra dose of steroids to keep me awake.

In January this year, I went to Oxford University and spent 2 terms studying women artists, and this summer, I went to Sweden for the birth of my first grandchild. I am not back to how I was before I became ill, but there have been some really joyous moments. Life is not the same, but it is still good.

Hot Topic

Top tips for managing symptoms of AL amyloidosis

AL AMYLOIDOSIS CAN PRODUCE MANY DIFFERENT SYMPTOMS IN DIFFERENT PEOPLE. HERE WE ANSWER QUESTIONS PEOPLE ASK ABOUT SYMPTOMS IN AL AMYLOIDOSIS, AND GIVE MORE INFORMATION ON MANAGING SYMPTOMS.

Why can AL amyloidosis cause so many different symptoms?

AL amyloidosis happens when an abnormal protein called amyloid builds up in different parts of the body. Symptoms will depend on where the amyloid is deposited around the body. This is different for different people. Parts of the body affected can include the heart, kidneys, nerves, and skin.

If I have one type of symptom, will I later develop other ones?

Not necessarily. Most patients will have more than one part of their body affected, but will not experience all possible symptoms.

Will my symptoms improve after treatment?

If your treatment is working, generally your blood tests will improve first. Your symptoms will gradually improve in most cases, but this may take longer than the blood tests.

Some symptoms may not resolve completely after treatment if damage has happened that cannot be fully reversed. You may also have symptoms due to side effects of your treatment. These generally resolve after the treatment is finished, although some may persist.

Effects on the heart

Many AL amyloidosis patients have amyloid deposits on their heart. Your healthcare team will give you the best advice for managing your symptoms.

Symptoms may include:

- **Swelling in the legs or around the abdomen, or rapid weight gain**
- **Coughing and breathlessness**
- **Heart beating irregularly**
- **Dizziness when you stand up**
- **Fatigue**

Effects on the kidneys

Kidney disease can happen when amyloid blocks the kidney tubes and stops them working properly.

Symptoms can include:

- **Swelling in the legs or around the abdomen, or rapid weight gain**
- **Coughing and breathlessness**
- **Tiredness**
- **Lower appetite**
- **Frothy pee (urine)**

Top tips for managing heart and kidney related symptoms

1. **Restrict the amount of fluids you drink (you will be advised on how much to have)**
2. **Restrict the amount of salt you eat**
3. **Check your weight daily so you know quickly if you have extra fluid in your body**
4. **Do regular gentle exercise. Your healthcare team will advise what is suitable for you**
5. **Stand up slowly if you feel dizzy. Try stretching and moving before standing**
6. **Practice breathing techniques if you often feel short of breath**

AL amyloidosis and the kidney Infosheet

AL amyloidosis and the heart Infosheet

One of the main ways these symptoms will be treated is by treating the AL amyloidosis itself. Your healthcare team may also give you specific treatments for complications of kidney disease. These may include blood pressure medicine, water tablets (diuretics), and treatment for anaemia (which means lack of red blood cells).

Effects on the digestive system

Digestive symptoms (such as diarrhoea or constipation) can be caused by amyloid damage to the nerves, or amyloid deposits on the digestive system itself.

Symptoms can include:

- **Nausea**
- **Diarrhoea**
- **Feeling full when you have only eaten a little food**
- **Weight loss due to amyloid deposits reducing how well you absorb nutrients from your food**

You will be given treatments to help with these symptoms.

Top tips for managing digestive symptoms

1. **Eat little and often, or try to plan meals around when you feel most hungry**
2. **Stay hydrated as vomiting and diarrhoea can dehydrate you**
3. **Take anti-sickness medicine regularly as prescribed**
4. **Tell your healthcare team if your treatments are not working well, so you can try something different**
5. **Avoid cooking foods with strong smells or keep a window open while cooking**
6. **Fresh air can help – sit near an open window or outside**

AL amyloidosis Essential Guide (page 37 onwards)

Effects on the nervous system

If amyloid builds up on the nerves, this can cause different symptoms depending on which nerves are affected.

The nerves that can be affected are:

- Nerves that send signals such as pain and touch
- Nerves that sense our position and control movement
- Nerves that control bodily functions (such as blood pressure, heart rate, digestion and the bladder). These are called autonomic nerves

Symptoms may include:

- **Pain, tingling or numbness in the hands and feet**
- **Dizziness when you stand up**
- **Nausea, diarrhoea or constipation**
- **Difficulties storing and releasing urine**

Read more top tips for different symptoms in the Infosheets below.

Peripheral neuropathy (AL amyloidosis) Infosheet

Autonomic neuropathy (AL amyloidosis) Infosheet

Side effects of AL amyloidosis treatments

Each type of treatment has its own side effects. The same treatment can cause different side effects in different people. Most side effects are temporary and can be managed. In some cases your treatment dose may be reduced, or you may be switched to a different treatment if side effects are too much to manage.

Side effects of AL amyloidosis treatment include:

- Pain, tingling or numbness in the hands and feet
- Tiredness
- Increased infections
- Increased risk of bleeding and bruising
- Skin rash
- Nausea or vomiting
- Mood changes
- Difficulties sleeping

Whether you experience any of these side effects will depend on the treatment you are being given.

Information and support

There are many sources of support for you:

Your healthcare team
Tell them if you have any new or worsening symptoms. Tell them if your treatments for symptoms are not working well, so you can try something different.

The Myeloma UK Infoline and Ask the Nurse service
We are there for you if you have AL amyloidosis, or if you are a friend, family member or carer

Other patients
It can help to talk about how you and other people manage symptoms. Support groups may be available near you or online.

Information booklets
Booklets about different aspects of AL amyloidosis are available on our website at myeloma.org.uk

ASK THE NURSE

Ellen Watters, Rebecca Huntley, Fern Pallister **Myeloma UK Information Specialists**

I have been diagnosed with renal AL amyloidosis. What does this mean?

AL amyloidosis can affect almost any of the body's organs and tissues by causing a buildup of an abnormal protein resulting in amyloid deposits. AL amyloidosis that affects the kidneys is called renal AL amyloidosis.

The kidneys are responsible for a range of important functions. They filter the blood to move waste products from the body and into the urine. They also return essential vitamins, hormones and glucose back into the blood. They maintain the balance of water in the body and control blood pressure.

Amyloid deposits that build up prevent normal renal function, and lead to a range of symptoms, including:

- Fatigue
- Swelling typically in the legs and abdomen
- Rapid weight gain due to oedema (water retention)
- Loss of appetite
- Difficulty breathing that is worse at night when lying down
- Frothy urine due to protein being excreted from the kidneys

Treatment for AL amyloidosis aims to reduce the production of amyloid proteins, allowing the body to clear the existing deposits, and in turn manage and reduce symptoms. Treatment is usually a combination of medicines that control amyloid production, and supportive care to manage symptoms.

I have constipation but I eat a healthy diet. I am also struggling to put weight on.

Constipation in AL amyloidosis is not uncommon. Sometimes amyloid deposits in the bowel, or damage to the nerves that control bowel function can cause constipation, as well as a potential side effect of treatment.

Regarding your struggle to gain weight, our Infosheet on Diet and nutrition in AL amyloidosis has some information about eating well for AL amyloidosis patients. Sometimes patients who struggle to put on weight are advised to consume more calories than usually recommended to the general population by the NHS in their 'eat well' guidance.

Your medical team may be able to refer you to a dietitian who can give advice on how many calories you should try to consume and any changes you should make to your diet. They can also offer you high calorie supplement drinks if appropriate.

Report any new or increasing symptoms to your healthcare team (GP, haematologist, or clinical nurse specialist) as soon as possible, so that they can investigate thoroughly and identify a cause and possible treatment options.

Constipation (AL amyloidosis) Infosheet

AL amyloidosis and the kidney Infosheet

Diet and nutrition (AL amyloidosis) Infosheet

nhs.uk/live-well/eat-well

Our Information Specialists don't just specialise in myeloma. They are here for anyone affected by AL amyloidosis, including patients, family members, friends and carers.

If you have questions, concerns or just want someone to talk to about AL amyloidosis, call the **Myeloma Infoline** on **0800 980 3332**, use our online form at **myeloma.org.uk/AskTheNurse** or email **AskTheNurse@myeloma.org.uk**

Introduction to Support Groups

"Being with people who just 'get it'. Feeling connected, supported and safe."

Myeloma UK runs a Support Group programme which provides patients, families and friends with the opportunity to connect with a community of people who truly understand what it's like to live with an AL amyloidosis diagnosis.

Currently, there are 77 Support Groups across the UK and Ireland. One Support Group is specifically for people with AL amyloidosis, but all myeloma Support Groups welcome people with AL amyloidosis, as well as their family members and carers. The exception to this are ones designed to support specific groups of people, such as the **Friends and Family myeloma Support Group**, and the **50s and Under myeloma Support Group**.

Normally, Support Groups cater for people in their local area, however, some groups that meet online are open to members from across the UK and Ireland.

Having a support network to help navigate the journey can make a world of difference. Support Groups can be the bridge between feeling isolated and feeling understood.

"The biggest help the group gave me was being able to see people who had the same illness as me leading normal lives. It gave me hope that I would be able to get back to being able to do things."

Jackie, Milton Keynes Support Group member

"Having attended the Support Group, I feel much more optimistic for my partner."

Jayne, Support Group member

"The support group gives me the opportunity to meet with and talk with others in the same situation. Not just those with a diagnosis but their partners as well."

Pauline, Teesside Support Group member

What if I don't have a local Support Group?

If you don't have a Support Group in your local area, why not start one? The Myeloma UK Support Groups Partnership Programme is here to help anyone who runs a Support Group or would like to set up a new one.

The programme gives Support Group Leaders exclusive access to the Partnership Hub, a dedicated online platform, and a community of Leaders that they can share ideas with. The platform offers a wealth of information on setting up a new group and how to sustain it, best practice guidelines and templates to use for your Support Group.

Setting up a new group starts with someone who is passionate about providing support to others, and Myeloma UK are on hand for support throughout the process. Over half of Support Group Leaders are patients, carers, or family members.

You don't need a medical background to run a group; just a desire to help and support others.

"The Leaders Network within the Partnership Hub has been a great source of knowledge and advice for me. It's a comfort knowing they are there if I have any questions or need support."

Samantha, Derby Support Group member

"We have found that the Partnership Programme set up by Myeloma UK is a hugely positive step forward in patient support."

Iain, Milton Keynes Support Group member

If this sounds like you, please get in touch with Prabs Parmar in the Support Groups team at **supportgroups@myeloma.org.uk**

MyelomaUK
Support Groups
Partnership Programme

AL amyloidosis Advocacy

Paving the way for new treatments

It has been nearly 2 years since the first National Institute for Health and Care Excellence (NICE) approval for an AL amyloidosis treatment: DaraCyBorD.

Although there have been no subsequent NICE assessments, there are several ongoing clinical trials investigating new treatments for AL amyloidosis. This includes treatments that are currently being used to treat myeloma.

This is excellent news for people with AL amyloidosis. However, we know from our experience that generating enough evidence through clinical trials is only the first step to securing access on the NHS.

We have been working hard behind the scenes to remove potential barriers to access by pushing for greater use of pricing agreements, specifically for treatments used in more than one condition.

This is especially relevant for AL amyloidosis, which is often treated with the medicines used for myeloma.

Recently, we responded to a consultation with NICE about when these pricing agreements could be used. In our response, we asked for changes to the criteria for when the agreements could be used and highlighted their importance, particularly for people with rare conditions, such as AL amyloidosis.

This is an important step to ensuring these agreements are used more routinely, and we will keep pushing to ensure this will not be a barrier for future AL amyloidosis treatments.

Treatments for AL amyloidosis currently being assessed in clinical trials globally

Bispecific antibodies

- Teclistamab
- Elranatamab
- Linvoseltamab

Antibody Drug Conjugates

- Belantamab mafodotin

CAR-T cell treatments

- Ide-cel
- Cilta-cel

Use the **Myeloma UK Clinical Trial Finder** to find out about ongoing clinical trials in the UK

Tell us how we did

Have you used any of our services?

We want to hear from you!

Myeloma UK is running a survey to understand how we can better support patients and those close to them. Whether you used our information booklets, our online resources or our joined in on the discussion forum, we want to know your thoughts.

There's also the opportunity to share any suggestions for improvements and future services.

Fill in the survey at **myeloma.org.uk/services-survey**

Can you help end delays in diagnosis?

This Christmas, we're determined to tackle delays in myeloma diagnosis.

But we need your help.

Find out more about the progress your support is making, what's coming next and how you can help at **myeloma.org.uk/xmas**

Scan me!

THE ULTIMATE RIDE EXPERIENCE

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10TH ANNIVERSARY

If you or any friends or family want to find out more about taking part please email the Ride Team at **ride@myeloma.org.uk** We'd love to hear from you!

MyelomaUK

Sign up today at ride.myeloma.org.uk

MyelomaUK

We're here for everything a diagnosis of AL amyloidosis brings

Call our **Myeloma UK Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.

Get answers to your questions by emailing **AskTheNurse@myeloma.org.uk**

Learn about AL amyloidosis from experts and meet other patients at our **Infodays** and **Digital Infoday Sessions.**

Order or download our **information booklets**, which cover all aspects of AL amyloidosis – call **0800 980 3332** or visit **myeloma.org.uk**

Join your nearest **AL amyloidosis Support Group** to meet up and talk to other people face to face or online.

Visit **myeloma.org.uk**, a one-stop-shop for information on AL amyloidosis; with videos, news and articles to help you keep up to date and live well with AL amyloidosis.

Use the **Discussion Forum** for the opportunity to share experiences and advice about living with AL amyloidosis.

Get matched up with a trained **Peer Buddy** for one-to-one support from someone with direct experience of AL amyloidosis.

Help make myeloma history by **fundraising and donating**. Email fundraising@myeloma.org.uk or call **0131 557 3332** to find out ways you can help.

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