2017 Patient and Family Infoday videos available

If you didn't manage to get to our annual Patient and Family Infoday last year, or would like to refresh your memory about what was discussed, videos from the day are now available to view on our YouTube channel at: www.youtube.com/user/MyelomaUK/playlists

They include Dr Helen Lachmann talking about complications and side effects in AL amyloidosis and Dr Ashutosh Wechalekar discussing treatment strategies.

The 2018 AL amyloidosis Infoday will be held on Friday 16 November 2018 at Friends House, Euston Road, London. For further information or to book a place please contact Hollie on 0131 557 3332 or visit www.myeloma.org.uk/infodays.

We're currently planning the programme for this year’s Infoday, so if you have any topics you would like to see covered on the day, please email your suggestions to infodays@myeloma.org.uk.
Development of NEOD001 discontinued

The development of the once promising monoclonal antibody drug NEOD001 has been halted due to efficacy concerns. NEOD001 had been designed to target the abnormal protein (amyloid) that builds up in organs in AL amyloidosis and to help the removal of deposits. The drug had been investigatd in the phase IIb PRONTO trial and was being investigated in the phase III VITAL trial and its open label extension trial. Although the drug had been generally safe and well tolerated, the results from the PRONTO trial showed that it did not meet its primary or secondary endpoints. Prothena Therapeutics Limited, the company who developed NEOD001, had a futility analysis carried out on the VITAL trial and subsequently decided not to continue developing the drug.

3D modelling may improve understanding of cardiac amyloidosis

A new way of studying interactions between cells in cardiac amyloidosis has been developed by scientists in the USA. Previously, 2D models have been used to study cardiac amyloidosis in the laboratory but their limitations mean they aren’t fully representative of the real-life cardiac environment. The new 3D model allows the entire surface of each cell to be exposed to the surrounding environment, facilitating more realistic cell to cell contact and simulating the real-life environment of an AL amyloidosis patient more accurately. It is hoped that this model will help scientists to understand the ways cells interact with each other in cardiac amyloidosis and therefore potential future targets for treatment.

First AL amyloidosis patient successfully treated with venetoclax (Venclyxto™)

The novel drug venetoclax has been used successfully to achieve a complete response in an AL amyloidosis patient in the USA. Venetoclax belongs to a class of drugs called pro-survival inhibitors, which work by accelerating cell death. It targets a protein called BCL-2 which is found in higher amounts on abnormal plasma cells than on healthy cells. Venetoclax may be particularly useful for patients with the genetic abnormality t(11;14), which is the most common genetic abnormality in AL amyloidosis, affecting nearly half of all patients. Venetoclax is currently being investigated in combination with dexamethasone for relapsed or refractory AL amyloidosis in a phase I trial.
What is chemo brain?
Chemo brain is used to describe the mind and memory problems that patients experience, usually due to the effects of treatment. Everyone can be affected differently; in general, though, it is a feeling of fogginess, of being out-of-sorts and struggling to remember words or things.

Most people who experience chemo brain can still carry on with everyday activities but will find that certain tasks are harder than they used to be. The impact of chemo brain usually depends on what and how much you are doing, and often it is more noticeable once you are back at work or if you are trying to juggle many things at once. It can be incredibly frustrating and stressful, particularly if it is hindering your normal activities.

How to cope with chemo brain
Although chemo brain is so called because of the effects of treatment - for example it is particularly common after high-dose therapy and stem cell transplantation - other factors such as tiredness, infection and emotional state increase the likelihood of developing chemo brain. Minimising fatigue, stress and anxiety can help ease the symptoms of chemo brain.

Discussing the problem with your nurse specialist may allow them to make some suggestions about how to cope with chemo brain. Some patients find that complementary therapies such as massage or aromatherapy help to reduce stress.

Although it can be frustrating not being able to find a word or forgetting something you were meant to do, try to be kind to yourself and don’t be discouraged. Explain to your friends and family what you’re dealing with and ask them to be patient with you.

Don’t be too disheartened; many AL amyloidosis patients are in the same boat as you and for the majority of patients mind and memory problems are short-term. Although it can take a while before you feel fully functioning, and in some cases it may take up to a year or so, chemo brain usually eases once you have finished treatment.

Summary
Chemo brain is a significant side effect brought about usually by treatment, and can affect daily life. However, it is normally short-term and will improve over time. Try reducing stress and managing fatigue to help lessen your symptoms and speak to your nurse specialist about it.

Practical tips
- Write important details down – use post-its, a notepad or noticeboard
- Put everything in a diary or wall calendar
- Set alarms and reminders on your phone
- Take physical exercise
- Do mental exercises like puzzles and crosswords
- Take time in the evening to reflect and process the day
- Rest well
- Tell your doctor, nurse, family and friends so you don’t have to cope on your own
My name is Lynne and I live in Caerphilly, South Wales with my husband Gary. Between us we have five children and five grandchildren.

Prior to 2000 I’d had very little in the way of ill health. I’d been with my employer since 1979 and hadn’t had more than the odd week or two sick leave in that whole time.

And then everything changed. In January 2000 I was diagnosed with breast cancer and had a lumpectomy. Two years later another lump was found and this time I needed a mastectomy. Later that same year a tumour was found on one of my ovaries, and a total hysterectomy was carried out in February 2003.

During my pre-op blood tests for the hysterectomy, paraprotein was found, so a bone marrow biopsy was carried out. I was referred to haematology and diagnosed with Monoclonal Gammopathy of Undetermined Significance (MGUS).

After yet more health issues, I thought enough is enough. I felt like I’d been on a merry go round which no one would let me get off. I was now “healthy” (apart from the MGUS) and whilst I’d remained strong and positive during that time, my mind now took over. I became overly self-conscious about my body image. While I wasn’t able to control the physical scars, I focused on what I could change. I took up walking which I found to be very therapeutic, and I joined a local rambling group.

This continued until 2009 when Gary and I got together. I was truly in love and with this happiness came peace within myself. I enjoyed life and hoped that the future would be rosy.

In 2010 I began experiencing symptoms of carpal tunnel syndrome in both wrists. My work involved using a computer so I put it down to that. I had cortisone injections and then surgery in late 2011. The right wrist responded well, the left not quite so well, but it was a lot better than it had been.

(Now, with hindsight, I wonder if this was the first symptom of amyloidosis?)

From November 2013 my balance starting deteriorating. I began to experience issues with my hands and feet - some parts I couldn’t feel and others became hypersensitive. It became more and more difficult using my fingers. My right leg ached a lot and I couldn’t walk any distance before feeling exhausted.

Gary and I married in August 2014 and honeymooned in Crete. We couldn’t understand why I found it so difficult to walk short distances, I needed to hold onto him because my balance was awful and I found it painful even to walk around the poolside without shoes on. Gary had to put my jewellery on because I couldn’t use my fingers. We both agree that it wasn’t quite how we’d envisaged our honeymoon!

I saw a neurologist on New Year’s Eve 2014. Nerve conduction studies showed that I had ‘severe axonal and sensory neuropathy’ along with muscle wastage.

In February 2015, I had my 6 monthly appointment with the haematologist. My paraprotein had been rising very slowly over the last few check-ups so I had another bone marrow biopsy. It showed that my MGUS had now progressed to smouldering (asymptomatic) myeloma and I was transferred to the myeloma clinic.

My myeloma consultant wasn’t convinced that the neuropathy was due to the myeloma and wanted me tested for amyloidosis.

Amyloid what??!! I’d already spent ages researching myeloma and now I was being told that I could have something else I’d never heard of.

I was started on six cycles of RCD (Revlimid® (lenalidomide), cyclophosphamide and dexamethasone) in April 2015, to be followed by a high dose therapy and stem cell transplant (HDT-SCT). I tolerated the chemo quite well, although as many readers may have experienced, diarrhoea with the lenalidomide and many a sleepless night courtesy of the dexamethasone followed!

My first appointment at the National Amyloidosis Centre (NAC) was in May 2015. I was a little nervous, but was made to feel at ease straight away.
At the consultation I was told that I probably had AL amyloidosis but that it couldn’t be confirmed until they had the results of the rectal biopsy I’d had in April. The results arrived within 2 weeks, and it was positive for amyloid. I was also referred to The National Hospital for Neurology and Neurosurgery in London – their verdict was that it was very likely my persistent neuropathy was due to amyloid deposits.

There we have it. A dual diagnosis of myeloma and AL amyloidosis. The one good thing was that the treatment for both diagnoses was the same.

On 8 November 2015 I went into hospital to have the stem cell transplant. This was no walk in the park, but I knew it had to be done. I went home 3 weeks later. My recovery had now begun!

I had a complete loss of appetite, which took months to return to normal. I even struggled to take my medication as everything made me feel queasy. Gary now had to cope with looking after me, trying to get me to eat, to take my tablets, clean the house, look after our dog and after 2 weeks had to go back to his full time shift work. Every day I had a long list of things for him to do. My daughter who lives nearby helped out as much as she could but she also worked full time. I felt useless!

Very gradually I started to recover. February 2016 saw us go back to the NAC for my first follow up appointment. A short time after that I was told I was in complete remission from both the myeloma and AL amyloidosis. That was tremendous news. I began to feel better in myself and my hair started to grow back (albeit grey and curly).

Although I was getting stronger, there were still so many things that I couldn’t do due to my mobility and neuropathy issues. I found it very frustrating. I had been fiercely independent, and now I had to depend on my family to do things for me. It went totally against my nature but there was nothing else I could do.

During this time Gary didn’t seem to be that well, although I knew he was rushing around after me and worrying about me. He was told he had angina and had to have a stent fitted in his heart. He finally told me that he hadn’t been feeling well for months but his concern and worry had only been about me - now we were both recovering!

My family were very supportive, but I knew I needed to try and regain some normality.

I joined the local Myeloma Support Group in September 2016 and found it helpful talking with other patients about their experiences.

At the end of 2016 Gary asked me what I was going to do - I couldn’t sit at home all day. My mind started to whir, what was my way forward?

In early 2017 I decided to set up a local AL amyloidosis Support Group, because, although the NAC forum was very helpful, I wanted to meet other patients face to face and the other Support Groups were in Scotland and London. With support from Myeloma UK, I promoted the Group and a few people contacted me. We arranged a venue, date and time to meet up and it went very well.

We talked about our histories and experiences and a future meeting was planned.

Life started to take on a whole new meaning and I began to get busier as the Group grew. I decided to widen the “catchment area” and reach out to patients in the South West of England too. Again, with the help of Myeloma UK and also via the NAC forum, people started to contact me, and Gary and I (on his days off) embarked on our travels.

I now run three AL amyloidosis Support Groups – we meet in Cardiff, Exeter and Bath – as well as chairing a Myeloma Support Group.

Life is very busy. I spend a lot of time on the phone talking to people from the Support Groups and to AL amyloidosis patients who want a chat. I am astounded to find that every patient's journey has been different and the disease has affected them in different ways. The strength everyone finds is nothing short of amazing.

I am still restricted a lot in what I am physically able to do, and it affects mine and Gary’s lives tremendously, but I’m stronger now than when I was diagnosed. My family have been amazing throughout it all.

I count my blessings every day for the treatment I received and I try not to think about how long I’m likely to stay in remission.

I would like to say a huge thank you to my family, all of my amyloidosis and myeloma friends, my healthcare team, Myeloma UK and the NAC. You’ve all been magnificent. I am truly humbled and grateful.
CARER’S EXPERIENCE

My name is Gary Dixon, I am 54 years old and I live in Caerphilly, South Wales. I work in security and I’m working full time. I have been there for 30 years, and previously I was in the Royal Navy.

Lynne and I got married in August 2014. She was diagnosed with AL amyloidosis in June 2015, having been diagnosed with myeloma two months before. This was not the start of married life together that we had foreseen.

Initially, like most people we have spoken to, we had never heard of AL amyloidosis, so everything was new to us; we didn’t know what to expect and how it would affect Lynne.

From the moment that Lynne was diagnosed, she wanted to know everything and anything to do with AL amyloidosis. Any bit of information was taken in and stored, whether it was on paper, leaflets or through talking to someone. On the other hand, I couldn’t take it all in. I only wanted information that was relevant at the time; small chunks, small bits of information that I needed to get by – certainly no information about what the future would bring, and nothing about how this condition was going to change our lives.

The changes have been quite dramatic and quick. Lynne has AL amyloidosis within the nerves and it has affected her hands and feet, so her dexterity and mobility are greatly affected, and she’s currently taking gabapentin for the nerve pain. Before Lynne’s diagnosis, she used to do coastal walks around Cornwall and Devon, and her love for Scotland would see her walking around lochs and enjoying the beautiful scenery, a very outdoor person. Now she struggles to climb the stairs in the house, and has to lean against the door frames when she stops to talk to me. We have made many changes to help Lynne in her daily life, such as buying a mobility scooter, changing our car (so we can take the mobility scooter with us), putting hand rails up, removing the bath and having a walk in shower in its place.

Lynne went into hospital for a stem cell transplant in November 2015 – a traumatic and difficult experience for her and me. Whilst visiting Lynne at every opportunity, doing a full time job and looking after Mikey (our golden retriever), I was also developing problems of my own. Little did I know that I was suffering from angina.

After Lynne’s time in hospital it was lots of care at home, trying to make sure she was comfortable and recovering. During this time we thought it would be a good idea to decorate our three bedrooms, so I was using every opportunity between work and caring for Lynne to complete the rooms as soon as possible. All this and my condition was getting worse. I just thought I was getting breathless and having chest pains because I was unfit, but in August 2016 I ended up having a stent fitted in one of my arteries in the heart. I’m pleased to say all is well now.

After the stem cell transplant when Lynne was allowed home, things were very difficult. Because of the risk of infection, we had to be very careful in everything we did; hygiene was a priority, everything had to be washed and washed again, nothing left out and everything put away. The things you take for granted had to be rethought, and having a golden retriever with muddy paws didn’t help. Lynne would also have a list of things for me to do, as she was sat there thinking of what needed to be done. I have to admit it was a most testing and trying period of the treatment plan.

Every decision we make, whether it is regarding something small, like popping
out to the shops, or planning a holiday, AL amyloidosis and its effect on Lynne needs to be taken into account. How far do we need to walk, is there seating, what do we need to take, are there disability facilities? Gone are the days when we could go and do something on a whim – even a small journey in the car tends to end up with a boot full of “stuff”.

The condition has affected me very much: it’s hard seeing Lynne like this. It upsets me so much, both emotionally and physically. I am not always honest with Lynne about how it is affecting me, how can I be? I will always put her and her needs first. It is difficult to try to keep my emotions to myself so I don’t upset Lynne as she is the one with the condition.

People say to me “you need your own space, make time for yourself, find a hobby”. What I have discovered, however, is that these words are easier said than done. At what point can you honestly distance yourself from how AL amyloidosis is affecting the one you love?

I bought a motorbike, a custom bike I had fancied owning for years, so I could ride the open road. I also joined the Royal British Legion Riders, a group of likeminded people helping others and enjoying each other’s company and camaraderie. Whenever possible (weather permitting), this has helped me to get away and get my head clearer, but I still worry whether Lynne is ok while I’m out.

The National Amyloidosis Centre (NAC) website has given us information regarding support, as have Myeloma UK and the amyloidosis forum when needed. The doctors, nurses and staff at the Royal Free Hospital, London, have been brilliant with us – no question is too big or too small, and they answer with care and compassion. For such a rare disease, there always seem to be a lot of sufferers when we visit the NAC.

Because of her diagnosis, Lynne identified a need for local support within the South Wales area. This now comes in the form of regular meetings in Cardiff (in a pub!) where we meet to discuss all topics, not just amyloidosis, and maybe have a meal and drink. Lynne also spends a lot of her time making phone calls to other amyloidosis patients, giving support or just having a natter. Lynne has recently started Support Group meetings in Bath and Exeter, and we have had so much positive feedback from everyone.

We have met such lovely people within these groups. Sharing stories and experiences, knowing you are not alone in the things that you do, and being able to talk to other carers really helps.

I would like to think that more support and consideration can be given towards carers – it’s not just the patients that have to go through this disease.
AL amyloidosis Patient and Family Infoday

Friends House, London
9.00am - 4.00pm, Friday 16 November 2018

Chair: Prof Philip Hawkins, Professor of Medicine and Clinical Director, National Amyloidosis Centre, London

**Patient and Family AL amyloidosis Infodays bring people affected by AL amyloidosis together to share experiences, hear from experts and to learn more about the support Myeloma UK provides.**

- Learn about current treatments and latest research
- Hear from patients and carers about their experiences
- Participate in interactive breakout sessions
- Meet others in a similar situation

For more info call 0131 557 3332 or visit www.myeloma.org.uk/infodays